

MED
Thesis
+Y12N
M2977
c.2

The Adaptation of Siblings to Children with Type 1 Diabetes

Shari A. Farmer

WIDE UNIVERSITY SCHOOL OF NURSING

2004

YALE
UNIVERSITY



CUSHING/WHITNEY
MEDICAL LIBRARY

The Adaptation of Siblings to Children with Type 1 Diabetes

Submitted to the Faculty
Yale University School of Nursing

In Partial Fulfillment
Of the Requirements for the Degree
Doctor of Nursing Science

Sheri A. Kanner

August, 2004

YALE MEDICAL LIBRARY

SEP 30 2004

Thesis
+Y12N
M2977
C.2

This Research is accepted in partial fulfillment of the requirements for the degree Doctor of Nursing Science.

Margaret Grey

Margaret Grey, DrPH, FAAN, CPNP
Associate Dean for Research Affairs
Independence Foundation Professor
Chair, Dissertation Committee

9/1/04

Date

Permission for photocopying or microfilming of "The Adaptation of a Sibling to a Child with Type 1 Diabetes" for the purpose of individual scholarly consultation or reference is hereby granted by the author. This permission is not to be interpreted as affecting publication of this work or otherwise placing it in the public domain, and the author reserves all rights of ownership guaranteed under common law protection of unpublished manuscripts.

Sheri A. Kanner
Sheri A. Kanner

9/1/04
Date

Acknowledgment

I am extremely thankful to faculty, colleagues, family and friends who contributed to the completion of my doctoral studies and to this dissertation. I am particularly grateful to Margaret Grey, who served as my advisor, mentor and supporter throughout my years of my doctoral studies at Yale University School of Nursing and to Dean Catherine Gilliss who served as my co-advisor. I have also been privileged to have had great input and support from Christine Emmons, Associate Research Scientist, Yale Child Study Center with regards to my data analysis. I am also grateful to have had on my committee Kathleen Knafl and Sheila Santacroce who served as readers for the defense of my proposal and dissertation and who provided much appreciated feedback and direction. I am also thankful to Ruth McCorkle, Chair, Doctoral Program, for her encouragement and support throughout my years of doctoral study.

My colleagues have been the source of great comfort and support and I am extremely blessed with their friendship. A special thanks to Kelley Newlin, Joan Rimar, Stephanie Tang, Bothyna Murshid, Susan Sullivan-Bolyai, Robin Whittimore, and Melony Martens.

My sincere appreciation is owed to the my co-workers and friends at the Center for Pediatric Medicine, Danbury, Connecticut for their constant support and encouragement during the dissertation process. I wish to personally thank Dr. Ana Paula Machado, Dr. Joanne Magner, Dr. Robert Golenbock, Dr. Nandini Kogekar, Dr. Vincent Garcia and Dr. Claire Bailey. Also special thanks to Judy Witters, Tricia Terentieff, Christopher Moody, Jennifer Handau, Karen Macaulay, Jennifer Malta, Judy McAvoy, Nicole Manka,

Kathy Beck, Susan O'Sullivan, Sandra Diehl, Hetal Chokshi, JR Morrison, Robin LaMontagne, Debra Senger and Elizabeth Moore.

A very special thank you is owed to my family, especially my parents, Lillian and Eugene; my brother and sister-in-law, Hal and Barbara; and my nephew Austin. They have always been there for me when I needed some extra support and guidance. And, they are the people that taught me much of what I know about families.

This student was partially supported by an award from the National Institutes of Health, National Institutes of Nursing Research, Fellowship Award Number F31NRO7506-01, an award from the American Society of Psychosomatic Disorders, and an award from the Connecticut Nurses' Association during the conduct of this study.

ABSTRACT

THE ADAPTATION OF A SIBLING TO A CHILD WITH TYPE 1 DIABETES

The siblings of children with chronic illness have been largely overlooked in most family health research in favor of the parent-child relationship. This dearth of knowledge becomes especially problematic when the goal of health care professionals is to deliver family-centered care to families with a child with a chronic illness. Type 1 diabetes is a common chronic illness of childhood, and as such, has a significant impact on not only the individual child but on the family as a whole. Awareness of the link between poor management and poor outcome, and of the genetic nature of the disease, might place additional stress on the families that may not be evident with some other childhood illnesses. Unlike other childhood chronic illnesses that may either improve with time or end with the death of the child, the severity of diabetes tends to increase as one moves along the illness trajectory.

The purpose of this descriptive study was to examine, within in the context of the family environment, the adaptation of children (8-14 years), to a sibling with type 1 diabetes guided by The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993).

The research questions were: (1) What are the coping strategies used by siblings of children with type 1 diabetes as measured by the Schoolager's Coping Strategy Strategies Inventory (SCSI)? (2) What is the sibling's appraisal of living with type 1 diabetes in the family as measured by the knowledge, perception, and mood subscales of the Sibling Perception Questionnaire? (3) How well do the siblings of children with type 1 diabetes adapt to living with type 1 diabetes in the family as measured by the Children's

Depression Inventory (CDI)? and (4) Using structural equation modeling, what are the relationships among family typology as measured by the Family Adaptability and Cohesion Scale (FACES II) and the cohesion subscale of the Coping Health Inventory for Parents (CHIP), social support and resistance resources as measured by the resource subscale of Family Inventory of Resources for Management (FIRM) and the social support and communication subscales of the Coping Health Inventory for Parents (CHIP), sibling appraisal as measured by the perception and mood subscales of the Sibling Perception Questionnaire (SPQ) and the Children's Depression Inventory (CDI) and sibling adaptation to living with type 1 diabetes in the family as measured by the Schoolager's Coping Strategy Strategies Inventory (SCSI), the knowledge subscale of the Sibling Perception Questionnaire (SPQ) and the global subscale of the Self-Perception Profile for Children (SPPC)?

The convenience sample included 128 siblings aged 8-14 years, who were recruited from a diabetes clinic located in a university tertiary care facility located in the Northeast. Data were collected with the FACES II, the FIRM, and the CHIP as well as the CDI, the SPQ, the SPPC and the SCSI.

The results revealed that the siblings used a variety of coping strategies including relaxation behaviors, distracting behaviors, social support measures and cognitive measures. The majority of the siblings felt that they had adequate knowledge about diabetes, appraised the experience in a positive manner and did not feel that the experience caused them to feel depressed. The structural equation model delineated a positive and significant relationship between social support and sibling appraisal and a

direct effect between sibling appraisal and sibling adaptation. Social support had a mediating effect on sibling adaptation through sibling appraisal.

The findings of this dissertation study may provide health care providers methods to identify those children who seem to be most affected by their sibling's illness. The long-term goal of the program of research is to design interventional programs within hospitals and community settings to assist siblings to adapt to living with type 1 diabetes in the family. Such involvement can afford the nurse the opportunity foster coping strategies and behavior patterns that may enhance the sibling adaptation to type 1 diabetes.

TABLE OF CONTENTS

CHAPTER 1

The Clinical Problem.....	1
Introduction.....	1
Pathophysiology of Type 1 Diabetes.....	2
Purpose.....	5
Conclusion.....	5

CHAPTER 2

Introduction.....	6
Theoretical Framework and Definitions of Concepts.....	8
Research Studies.....	17
Social support and family typology.....	17
Social support and sibling adaptation.....	19
Family typology and sibling appraisal.....	22
Social Support and sibling appraisal.....	26
Sibling appraisal and sibling adaptation.....	30
Appraisal, social support and sibling adaptation.....	40
Conclusions.....	45

CHAPTER 3

Methods.....	48
Design.....	48
Research questions.....	48
Sample.....	49

Description of population.....	50
Selection criteria.....	50
Operational definitions.....	51
Setting.....	53
Data Collection Instruments.....	53
Demographic Information.....	53
Parent Instruments.....	54
CHIP.....	54
FACES II.....	55
FIRM.....	57
Sibling Instruments.....	59
SPQ.....	59
SCSI.....	60
SPPC	62
CDI.....	65
Data Collection Procedures.....	67
Data Analysis.....	68
Data Screening.....	68
Analysis Methods.....	68

CHAPTER 4

Introduction.....	70
Description of Sample.....	72
Research Question 1.....	77
Research Question 2.....	86
Research Question 3.....	92
Research Question 4.....	95
The Hypothesized Causal Model.....	98
Model Identification.....	102
Estimation of Hypothesized Measurement Model.....	104
The Revised Measurement Model.....	109
Estimation and Testing of Revised Model.....	110
The Final Measurement Model.....	111

CHAPTER 5

Introduction.....	122
Coping Strategies.....	122
Appraisal.....	127
Adaptation.....	130
Relationships among Variables.....	133
Limitations	143
Nursing Implications.....	146
Conclusions.....	148

REFERENCES.....	151-171
-----------------	---------

APPENDICES

- A. Demographic Data Sheet
- B. Coping Health Inventory for Parents (CHIP)
- C. Family Adaptability and Cohesion Evaluation Scales (FACES II)
- D. Family Inventory of Resources and Management (FIRM)
- E. Sibling Perception Questionnaire (SPQ)
- F. Schoolagers' Coping Strategies Inventory (SCSI)
- G. Self-Perception for Children (SPPC)
- H. Children's Depression Inventory (CDI)
- I. Covariance Matrix

LIST OF FIGURES

Figures

1. The Resiliency Model of Stress, Adjustment and Adaptation.....	6
2. Hypothesized Structural Equation Model.....	97
3. Hypothesized Measurement Model.....	98
4. Hypothesized Causal Model.....	99
5. Final Measurement Model.....	113
6. Final Structural Model	119

LIST OF TABLES

Tables

1.	Comparison of Parent Instruments Based on Gender.....	52
2.	Descriptive Characteristics of the Siblings.....	73
3.	Descriptive Characteristics of the Child with Diabetes.....	74
4.	Descriptive Characteristics of the Family.....	76
5.	Total Scores on the SCS1.....	77
6.	Means, Standard Deviations and Ranges for the SCS1.....	78
7.	Means, Standard Deviations and Ranges for the SCS1 by Age.....	81
8.	Means, Standard Deviations and Ranges for the SCS1 by Gender.....	82
9.	Comparisons of SCS1 based on Age and Gender.....	83
10.	Responses to the Frequency Subscale SCS1 based on Gender.....	84
11.	Responses to the Efficacy Subscale SCS1 based on Gender.....	85
12.	Means, Standard Deviations and Ranges for the SPQ.....	86
13.	Means, Standard Deviations and Ranges for the SPQ by Age.....	89
14.	Means, Standard Deviations and Ranges for the SPQ by Gender.....	90
15.	Comparisons of SPQ based on Age and Gender.....	91
16.	Means, Standard Deviations and Ranges for the CDI.....	93
17.	Frequency Scores on the CDI.....	94
18.	Latent Variables with Critical Indicators.....	102
19.	Goodness of Fit Statistics for the Hypothesized Measurement Model.....	106
20.	Goodness of Fit Statistics for the Revised Measurement Model.....	111
21.	Latent Variables for Final Structural Equation Model.....	112
22.	Goodness of Fit Statistics for the Final Measurement Model.....	114
23.	Goodness of Fit Statistics for the Final Structural Model.....	116
24.	Error Terms of Indicator Variables in Final Measurement Model.....	117
25.	Loadings of Critical Indicators to Latent Variables.....	118
26.	Relationships between Latent Variables.....	120
26.	LISREL Estimates of Model Parameters.....	121

CHAPTER 1: THE CLINICAL PROBLEM

Introduction

The adaptation of a sibling to the illness of their brother or sister will be influenced by the family system, and as such the family system will be affected by the manner in which each family member individually copes with the challenges of a chronic illness (Williams, 1997). A better understanding of the psychosocial and family variables is of particular importance in families with a child that has type 1 diabetes given the complex relationship between psychological factors and health outcomes (Northam, Anderson, Adler, Werther & Warne, 1996). Families as interrelated systems represent a significant context for each member's health and also as the actual unit of care (Gilliss, 1991).

Successful management of type 1 diabetes is very time consuming as well as challenging (American Diabetes Association [ADA], 2001), and both the management of the disease and the fear of possible complications affect the entire family. In addition, the adverse effects on the parents' psychological well-being may be problematic (Adams, Peveler, Stein & Dunger, 1991). Unlike many other childhood chronic illnesses (e.g. cancer, asthma, cystic fibrosis, juvenile rheumatoid arthritis) that may either improve over time or end with the death of the child, the severity of type 1 diabetes can increase as one moves along the illness trajectory.

In addition to their usual parenting tasks, the parents of children with type 1 diabetes are called upon to monitor their child's glucose levels, insulin dosages and nutrition on a daily basis (Marcus, 1999). Often the needs of the child with diabetes become the focus of the parent's attention and brothers and sisters of children with a chronic illness may get the false message from their parents and other adults that they are not as important as

the child with diabetes (Deatrick & Knafl, 1990). Intellectually, the siblings may understand that the child with diabetes may need a lot of extra attention and care; however, this knowledge does not lessen the hurt and neglect that the siblings may experience. Consequently, these siblings may be vulnerable to problems such as low self-esteem or depression. Since chronic illnesses require long-term adjustment and adaptation for all members of the family, fostering adaptive behaviors in siblings of children with type 1 diabetes is an important aspect of delivering comprehensive care to the patient and family.

The majority of siblings faced with adversity will manage successfully. Children generally survive and often thrive even in the face of chaos and instability within the family structure (Adams, Peveler, Stein & Dunger, 1991). Despite the fact that most children and most families survive stressful life events, the majority of the current literature highlights family failure and maladaptation. With the emphasis of the present health care delivery system on health promotion and anticipatory guidance, research may be driven by studies that attempt to explain why families faced with crises and extreme hardships remain resilient to such adversity. Ideally, research should focus on both positive adaptation and negative consequences, in order to better understand how to foster resilience in children faced with similar circumstances in order to reduce their risk of adverse effects.

Pathophysiology of type 1 diabetes

Type 1 diabetes is the most common metabolic disorder of childhood and is characterized by beta cell failure resulting in the lack of insulin production. This type of diabetes, which accounts for only 5-10% of those individuals with diabetes, was

previously described by the terms insulin-dependent diabetes or juvenile-onset diabetes. The prevalence of type 1 diabetes varies from population to population across the United States, but is generally about 1.7 cases per 1,000 children younger than 20 and approximately 123,000 children in the United States (ADA, 2001). Overall, the annual incidence of type 1 diabetes in the United States is approximately 18 new cases per 100,000 children younger than 20 years of age. This translates to approximately 13,200 new cases each year. The risk of developing type 1 diabetes before the age of 20 is approximately 0.5% and the life expectancy for children with type 1 diabetes is approximately 20 years less than for those children without diabetes (ADA, 2001).

The etiology of type 1 diabetes is unknown; however, many factors have been hypothesized to contribute to the onset of the disease (Ekoe, Zimmet & Williams, 2001). It is clear that type 1 diabetes is an autoimmune disease which destroys the beta-cells of the islets of Langerhans in the pancreas. As a result, no insulin is produced which allows glucose molecules to build up to dangerously high levels in the blood. This leads to the classic symptoms of polyuria, polydipsia and polyphagia characteristic of type 1 diabetes (Maffeo, 1997). Genetic susceptibility is a necessary precursor to the development of the disease and certain histocompatibility leukocyte antigen (HLA) genes are thought to play a role in the genetic tendency to develop type 1 diabetes.

The diagnosis of type 1 diabetes is determined if the classic symptoms are present and a casual plasma glucose level is more than 200 mg/dl (11.1 mmol/l). Alternatively, the diagnosis may be established if the fasting plasma glucose level is more than or equal to 126 mg/dl (7.0 mmol/l) or the 2-hour plasma glucose level is more than or equal to 200 mg/dl on a glucose tolerance test (ADA, 2004). The hyperglycemia as a result of

diminished insulin production leads to the long-term complications of diabetes including blindness, neuropathies, renal and cardiac failure, and death.

The management of type 1 diabetes has been modified since the results of a large randomized clinical trial, known as the Diabetes Control and Complications Trial (DCCT) that was designed to examine the differences between conventional diabetes therapy and intensive diabetes therapy. Intensive therapy involves three or more insulin injections per day or insulin delivered by continuous subcutaneous insulin infusion, frequent blood glucose monitoring and stringent diet management (Kaufman & Halvorson, 1999). The DCCT included 1441 people (aged 13-39) with type 1 diabetes, 726 of whom had no baseline retinopathy and 715 of whom had mild retinopathy (DCCT Research Group, 1993). The results of the study indicated that intensive insulin therapy was associated with a decrease of 76% in the development of retinopathy, 39% of microalbuminuria, 54% of albuminuria and 60% of clinical neuropathy. There was, however, evidence of a two-to threefold increase in severe hypoglycemia and clinically significant weight gain related to intensive management. In terms of quality of life, the results did not indicate a difference between the persons in the intensive treatment group and the conventional treatment group. Since the release of these findings, the ADA (2004) recommends intensive therapy for most children over seven years of age to return the blood glucose levels to near normal in order to prevent the long-term complications associated with diabetes (Skyler, 1997). Consequently, the constraints of intensive therapy place additional demands on the family's time and resources that may potentially affect the sibling's ability to adapt to living with the illness.

Purpose

The purpose of this study was to identify siblings that adapt well, to determine those variables that foster positive appraisal and coping responses and to initiate the design of nursing interventions that will promote positive adaptation to living with type 1 diabetes. The Resiliency Model of Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993) was used as a conceptual framework to investigate this phenomenon. Ultimately the goal of this program of research is to develop a conceptual framework designed to assess the critical attributes of adaptation, the knowledge of which can be useful in planning family and community based interventions designed to enhance the sibling's adaptation to living with type 1 diabetes.

Conclusions

Chapter Two will review the literature and research of the current theory of the siblings' adaptation to living with type 1 diabetes. Chapter Three describes the research design, setting and sample, data collection procedures and analysis methods. Chapter Four presents an analysis of the data collected for the study. First, descriptive data on the demographic information are presented. Second, the first three research questions are discussed using descriptive data and t-tests. Third, a discussion of the final research question is presented using structural equation modeling. Chapter Five discusses the findings of the study with implications for clinical practice and future research.

Figure 1

This chapter begins with a description of the Resiliency Model (McCubbin & McCubbin, 1993). Subsequently, literature and research are reviewed in order to gain a better understanding of the current theory on the siblings' adaptation to living with type 1 diabetes. The content of the literature review is organized according to the relationships between and among these latent concepts as hypothesized in the final structural equation model. These hypothesized relationships include the following:

(a) the noncausal relationship between social support and family typology, (b) the causal relationship between social support and sibling adaptation, (c) the causal relationship between family typology and sibling appraisal, (d) the causal relationship between social support and sibling appraisal, and (e) the causal relationship between sibling appraisal and sibling adaptation. In addition, the literature review section explores appraisal as a mediating variable between social support and sibling adaptation.

Based on the proposition that living with a child with type 1 diabetes is a non-normative experience in which there may be greater stress than for families who are living with a child that does not have a chronic illness, the majority of previous studies have focused on the negative impact of the illness on the sibling. These findings across various types of pediatric chronic illnesses are consistent with previous conceptualizations about families with chronically ill children referred to as the non-categorical approach (Stein & Jessop, 1982). The non-categorical approach suggests that even though the characteristics of the chronic illness create needs specific to the condition, various pediatric chronic illnesses generate common issues regarding sibling adaptation. Using the non-categorical approach, the literature review section explores the effect of family typology, social support, and sibling appraisal on sibling

adaptation across a variety of childhood chronic illnesses. Therefore, studies specific to type 1 diabetes are addressed and compared with studies that investigate the response to other childhood chronic illnesses such as cancer, cystic fibrosis, asthma and juvenile rheumatoid arthritis.

Theoretical Framework

Using the Resiliency Model of Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993) as a conceptual framework, this descriptive study was intended to lay the groundwork for future study in the area of sibling adaptation to the presence of type 1 diabetes in the family. Many factors influence how a family does adapt to the added demands of type 1 diabetes (Siegel & Silverstein, 1994). The Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993) (see Figure 1) attempts to explain why some families recover and are deemed resilient while other families remain vulnerable and may even falter under the same set of circumstances. The following are definitions of the variables used in the Resiliency Model.

Definitions

Social Support

Social support is defined as the information exchanged among persons or between groups of persons outside the family system intended to enhance emotional well-being and self-esteem and promote an overall sense of belonging and affirming appraisal (McCubbin & McCubbin, 1993).

Family Typology

Family typology is defined as a set of basic family patterns of behavior that characterizes and explains how the family system typically operates and behaves. Family

typologies as described by McCubbin and McCubbin (1989) highlight those family characteristics that provide more successful adjustment and adaptation to stress. Using this classification system, families high in resiliency, coherence, flexibility, and bonding as well as those that value and participate in family time and routines, were considered stronger and more capable of enduring stress. Additionally, these families appear to recover more easily from the impact of stressors than families that do not possess such traits.

Sibling appraisal

Sibling appraisal is defined as the assessment the sibling makes of the stressor, the capability of managing the crisis and the ability to attach meaning to the changes in the family functioning. Appraisals are the evaluative processes through which a person determines why and how much disruption will ensue (Gamble & McHale, 1989).

Sibling adaptation

Sibling adaptation is defined as the outcome of efforts to bring a new level of balance, harmony and coherence. The sibling is able to stabilize with instituted patterns in place, promote his/her own development, and achieve a sense of coherence and congruency even when faced with a major change in the patterns of family functioning (McCubbin & McCubbin, 1993; Antonovsky, 1987).

Foundations for the current Resiliency Model stem from the classic work of Reuben Hill (1949), whose work has served as the predominant model for family stress research. Hill (1949) focused on the relationship between the stressors, resources and perceptions of the stressors that mediated and protected a family from deterioration in a crisis situation. McCubbin and Patterson (1981, 1983) revised Hill's model to better reflect the

realities of family stress. The Double ABCX Model was developed which has an emphasis on the description of the factors, particularly coping and social support, which facilitate family adaptation to a crisis. The Family Adjustment and Adaptation Response Model (Lavee, McCubbin & Olson, 1987; McCubbin & Patterson, 1983) followed as a natural extension of the Double ABCX Model with a focus on describing the processes involved in the families' effort to balance demands and resources. This model fostered the development of the Typology Model of Family Adaptation and Adjustment (McCubbin & McCubbin, 1987), which focuses on the established patterns of functioning (typologies) and family levels of appraisals as indicators of adaptation.

The Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993) has been used with various family structures and cultural and ethnic backgrounds. Kosciulek, McCubbin and McCubbin (1993) used the Resiliency Model as their conceptual framework when studying recovery from a head injury, and Atkins and Amenta (1991) in their work with families adapting to AIDS. Murata (1994) applied the Resiliency Model of Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993) to low-income African-American family interventions and Captain (1989) used the model when working with families dealing with alcoholism. The Resiliency Model provides a tool designed to assess family functioning and plan family-based interventions in order facilitate family adjustment and family adaptation (Danielson, Hamel-Bissell, Winstead & Fry, 1993).

The Resiliency Model of Stress, Adjustment and Adaptation is based on the theory of symbolic interactionism. Coined by Herbert Blumer (1937), the term symbolic interactionism was originally used to describe a person's interaction with the

environment. An important feature of symbolic interactionism is the emphasis on the person as an active participant in interactions (Fawcett, 1995). As such, people are thought to actively evaluate communication from others, rather than to passively accept their ideas. Additionally, symbolic interactionism is based on the assumption that individuals actively set goals based on their perception of the relevant factors in a given situation. The symbolic meaning of the event, the family typology, the availability of resources and support systems, and the family's repertoire of coping strategies are factors that influence how a family perceives and adapts to type 1 diabetes. For example, living with type 1 diabetes may be viewed as a crisis by one family and a challenge by a different family. Symbolic interactionism is useful with these families because it provides a framework for understanding the role of meaning in individual and family responses to the disruptions in life that result from type 1 diabetes (Saunders, 1997).

The resiliency perspective examines why some individuals are better able to adapt to crisis situations. McCubbin and McCubbin (1993) define family crisis as a continuous variable denoting the amount of disruptiveness, disorganization, or incapacitation in the family social system; it is a state of family system disorganization and denotes a demand for basic changes in the family patterns of functioning so that stability, order and coherence can be restored. Illnesses can be divided into those that have an acute onset and those with a gradual onset (Newby, 1996). Diseases with a gradual onset allow the family some time for adjustment to the illness and for family adaptation. Significant alteration of roles within the family system may evolve over time to adjust and adapt to the illness. Illnesses that generally strike quickly, such as type 1 diabetes, place the entire

family into an immediate crisis requiring major adjustments and adaptation to occur rather quickly.

Application of the Resiliency Model

It would be far too simplistic and narrow for health professionals to focus on siblings' response to the illness without a thorough assessment of the family's response to the illness (McCubbin & McCubbin, 1993). The Resiliency Model of Stress, Adjustment and Adaptation provides a conceptual framework to examine the family as a system of interacting individuals, personalities, and family characteristics, all of which influence the response of the family to a chronic illness. The model is divided into two phases, the Adjustment Phase and the Adaptation Phase, that shape the response of the family dealing with a crisis situation.

The family adjustment phase of the Resiliency Model of Stress, Adjustment and Adaptation may be described as a series of interacting components that shape the family processes and outcomes. Outcomes vary along a continuum from the more positive bonadjustment –in which established patterns of family functioning are maintained - to the other extreme of maladjustment- a family crisis that demands changes in the established patterns of functioning (McCubbin & McCubbin, 1993). The four major areas of family life affected by a crisis situation are interpersonal relationships, structure, function and development, well-being and spirituality, and community relationships and nature. As such, the family is a system and each of these domains has an effect on each other as well as on society at large.

In the face of a stressor such as a chronic illness, successful or unsuccessful family adjustment is determined by several interacting components. The stressor and the severity

of the stressor interact with the family's vulnerability. A stressor is a demand placed on the family that produces, or has the potential to produce, changes in the family system. The stressor could threaten the family's integrity and well-being over time (McCubbin, 1984). Vulnerability is determined by the accumulation of demands placed on the family system, and the effect of these demands based on the family's developmental stage (Olson, Larsen, & McCubbin, 1985).

The vulnerability of the family interacts with the family's typology, which is defined by a set of attributes that explains how a family operates or functions. Family typologies, in turn, interact with the family's resources. The critical family resources are economic stability, cohesiveness, flexibility, hardiness, shared spiritual beliefs, open communication, traditions, celebrations, routines, and organization (Curran, 1983). The family resources interact with family's appraisal of the stressor. The family's appraisal of a stressor may range from interpreting it as being uncontrollable and forecasting the family's demise to viewing it as a positive challenge. The appraisal of the situation interacts with the problem solving and coping strategies such as communication styles, seeking help from the health care community and extended family and community resources (McCubbin, 1979; McCubbin & McCubbin, 1989).

The interaction of all the above factors with a stressor produces a response that calls for management. Some stressors do not produce major hardships for the family, especially when buffered by strong coping and problem solving abilities, positive appraisals, adequate resources and a resilient family typology. A state of bonadjustment ensues when the family meets the stressor with only minor adjustments and changes in the family system. In a state of maladjustment, the hardships created by the stressor

demand more substantial changes in the family system, inclusive of family roles, goals and values. New patterns of family functioning are called for to reestablish harmony and balance (McCubbin, 1995). Situations of maladjustment generally result in a family crisis in which case adaptation is required.

When a stressor becomes a family crisis, it initiates the adaptation phase. With most chronic illness, family adaptation rather than adjustment is emphasized, since it is a more necessary response to the permanency of the condition. Understanding the phases and processes of adaptation of families with a child with type 1 diabetes is critical because positive adaptation during the early stages of the disease may prevent later difficulties (Auslander, Bubb, Rogge & Santiago, 1993). Illness stressors have variable effects on the family, and these effects are seldom confined to the child with the illness. Inevitably, changes in one family member affect the entire family system. This “rippling effect” (Glick, Clarkin, & Kessler, 1987) is not confined to any particular stage of the illness; the entire family can be affected by such changes throughout all phases of illness and the effects can last a lifetime.

Adaptation is the phrase used to describe the outcome of family efforts to bring about a new level of balance, harmony, coherence, and functioning in a crisis situation (Danielson, Hamel-Bissell & Winstead-Fry, 1993). The adaptation phase, as is the adjustment phase, is determined by a number of interacting components. Family adaptation becomes the central concept in the Adaptation Phase and is used to describe the outcome of family efforts to achieve a new level of balance and fit after a family crisis (McCubbin & Thompson, 1987). In a crisis situation, the family unit struggles to achieve a balance and fit at both the individual-to-family and the family-to-community

levels of functioning. The family is a system of interacting parts and a change in one part affects the whole system. Therefore, family efforts at adaptation affect all family members as well as the family's interaction with the community. Family adaptation is achieved through reciprocal relationships, whereby the demands of one member are met by the capabilities of another, so as to achieve a balance and fit at all levels of interaction (McCubbin & Thompson, 1987).

The pile-up of demands or stressors created by the crisis interacts with the family's level of resiliency or regenerativity. This pile-up of demands is especially evident in the long term care of a child with a chronic illness. The six categories of stressors relating to the adaptation to a chronic illness include: (a) the illness and related hardships over time, (b) normative transitions in individual family members and the family as a whole, (c) prior family strains accumulated over time, (d) situational demands and contextual difficulties, (e) the consequences of family efforts to cope, and (f) intrafamily and social ambiguity that provides inadequate guidelines on how families should act or cope effectively (McCubbin & Patterson, 1983, McCubbin, 1989). Sometimes the coping strategies, such as taking on a second job to handle a financial crisis, or consuming alcohol, which turns into a dependency, may produce additional unanticipated burdens on the already overtaxed family unit. These demands, created initially as a result of a positive effort, must be considered in the assessment of family pile-up (McCubbin & Patterson, 1983).

The components of demands and family typology interact with the family's resources that are supported by family and friends in the community and by the family's appraisal of the situation. McCubbin and Thompson (1987) identify several important

resources which may be used by the family in the adaptation phase including: (a) innate intelligence, which can enhance awareness and comprehension of the demands; (b) knowledge and skills acquired from education, training, and experience so that one can gain employment and perform tasks necessary for daily living; (c) personality traits (e.g. a sense of humor, extroversion etc.) which may facilitate efficacious coping behaviors; (d) physical and emotional health so that intact faculties and personal energy may be available for meeting family demands, (e) a sense of mastery, which is the belief that one has some control over the circumstances of one's life, and (f) self-esteem.

The family appraisal of the crisis situation interacts with the family's schema appraisal to achieve a level of congruency. Reiss and colleagues (1967) developed a worldview of family appraisal that describes how families develop, shape, and attach value to a set of accepted values, rules, goals, priorities, and expectations, which compose the individual family's schema. The interaction between the crisis and the schema creates a family meaning that is attached to the crisis of the illness and the adaptation that it requires. The appraisal interacts with the family's problem solving and coping repertoire to facilitate the adaptation of the family to the crisis situation. Family coping may be viewed as coordinated problem-solving behavior of the whole system that also takes into account complementary efforts of individual family members. (McCubbin & McCubbin, 1993). Family efforts at appraisal and coping bring family members to value, accept, and affirm changes over time facilitating bonadaptation. Families that do not achieve a satisfactory level of adaptation fall into the category of maladaptation. Certain circumstances such as the appearance of complications, a severe hypoglycemic or hypoglycemic reaction, a hospital admission, or even the death of an acquaintance with

diabetes can impose a tremendous amount of stress on the family system that was previously adapting well to living with diabetes (Brown, 1985). As a result, these families may return to a crisis situation and then must find an alternative method of adaptation. Many families experience a major situational crisis when a child who had previously been managed with subcutaneous insulin injections is started on an insulin pump; and it is not uncommon for such families to return to a crisis state until they have time to adjust to this new treatment modality. The present study will focus on the adaptation phase of the Resiliency Model of Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993).

Research Studies

Social Support and Family Typology

The presence of type 1 diabetes has a unique impact on the affected children and their families (Kager & Holden, 1992). The rigors of the diabetes regimen such as the need to monitor blood glucose levels, the administration of insulin, and the balance of exercise and diet govern the lives of the child and the family. Helping these children and their families both to manage diabetes and to accomplish the normal tasks of childhood requires a collaborative effort.

Social support implies more than superficial contact with people; it involves a qualitative exchange of communication in an atmosphere of mutual trust (Danielson, Hamel-Bissell, Winstead-Fry, 1993). Observations of the adaptation to the stressor of a chronic illness reveal that the family strategies of coping with a chronic illness are not created in a single instant and are not directed at a single stressor. Because the family is a system, coping strategies involve the management of various dimensions of family life

simultaneously including family communication, family bonds, family cohesiveness, family resources, and family support systems. Coping then becomes a process of achieving a balance in the family system that facilitates organization and unity and promotes individual growth and development (McCubbin & Thompson, 1987).

Family typology appears to foster resiliency through flexible structure, shared leadership, and mutual support (Danielson, Hamel-Bissell, Winstead-Fry, 1993). The resilient family is able to balance the needs of the child with the chronic illness with the other competing family needs. The family's resources such as time, energy, and money are allocated as fairly as possible among all family members. Families with sufficient resources and support systems may be able to counteract the potentially negative impact of living with a chronic illness. In fact, some families are able to turn the situation into one of growth for all family members (Leonard, 1991).

According to Steinglass and Horan (1987), a balanced family is better able to adapt to the demands imposed by living with a chronic illness. The balanced family organizes the day-to-day family routines to incorporate the needs of the child with the chronic illness, yet the chronic illness does not become the centerpiece around which all else resolves. Not surprisingly, families with a child with diabetes were described as more organized, perhaps in response to the treatment regimen implemented at home (Hagen et al., 1990). The resilient family does not attempt to be a "super" family, rather it realistically accepts less than perfect solutions (Leonard, Skay & Rheinberger, 1998). Likewise, Daniels, Miller, Billings and Moos (1986, 1987) concluded that, on average, the siblings of children with juvenile rheumatic arthritis functioned quite well and the family risk and

resistance factors showed significant relationships with functional status for patients, siblings and controls.

By encouraging key processes for social support, families can emerge stronger and more resilient through shared efforts. Selected social support and family research is reviewed to highlight potential problems in social support exchange as patients and families collectively cope with chronic illness. Although the previous studies did address how family typology plays a role in family adaptation in response to the world around them, the non-causal relationship between family typology and social support was not addressed in any of the aforementioned studies. In order to fill the gaps in knowledge, the present study investigated the non-causal relationship between family typology and social support by including these two variables in the structural equation model.

Social Support and Sibling Adaptation

The sibling's ability to adapt may be determined by the type, severity and visibility of the disease. Gath (1972) compared children who had a sibling with Down's syndrome to a control group. The investigators did not find an elevated incidence rate in adjustment in the group of children with a sibling with Down's syndrome. However, Gath and Gumley (1987) replicated this study 15 years later with a group of siblings of children with physical deformities without a specific diagnosis with siblings of children with Down's syndrome and found that the siblings of children with the undiagnosed physical deformity had significantly greater adaptation problems than the siblings of children with Down's syndrome. The authors speculate that the availability of social support available to the families of a child with Down's syndrome may help to promote the sibling's adaptation to the disease.

Likewise, Van Riper (2000) examined the relationships between family demands, family resources, family communication, family coping and sibling well-being in families with a child with Down syndrome using the Resiliency Model of Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993) as a theoretical framework. A convenience sample of 41 mothers and the sibling closest in age to the child with Down syndrome completed questionnaires mailed to their homes. The results suggested that the majority of the siblings had positive self-concepts. In addition, all four family variables were significantly associated with at least one of the indicators of sibling well-being.

Tew and Laurence (1973) investigated the effect of the degree of severity of the disease on the sibling's adaptation. Data supported the hypothesis that the siblings, aged 2-15 years, of children with spina bifida would score significantly lower than the siblings of a control group. In addition, these siblings were four times more likely than the control group of siblings of children without spina bifida to have adaptation problems because of a lack support systems to help them cope with the effects of living with a sibling with spina bifida. Additionally, a non-linear relationship between the severity of the illness and the sibling adaptation was noted with siblings of children with severe and moderate disabilities showing the most maladaptation followed by those with slight disabilities. The data from the above studies support the notion that a family open to interaction outside the immediate family system enhances the adaptation to a chronic illness and that there is a relationship between certain family risk and resistance factors, such as social support, and sibling adaptation to chronic illness.

According to Lavigne and Faier-Routman (1993), the degree of sibling psychological adaptation problems may vary across disease type. Lavigne and Ryan (1979) compared

the adjustment of 3 to 13 year-old siblings of pediatric hematology, cardiology and plastic surgery patients with siblings without a chronic illness. Group differences were not noted on measures of aggression or learning problems; however male siblings of the hematology patients were more likely to show signs of emotional disturbance than the female siblings. Among the younger siblings, there were significant group differences with the siblings of patients undergoing plastic surgery having an increased incidence of adjustment problems resulting isolation from external social support systems (Lavigne & Ryan, 1979). Lavigne, Traisman, Marr and Chasnoff (1982) replicated the above study in a sample of children with diabetes and their siblings in a qualitative study. Congruent with their previous research, and in contrast to some previous studies of siblings of children with chronic diseases, the siblings did not show elevated levels of behavior problems.

The outcomes of a structured, educational and support group intervention for 22 conveniently selected siblings, aged 8-15 years, of children with various chronic illnesses (cancer, cystic fibrosis, diabetes, spina bifida) participated in the Intervention for Siblings Experiences Enhancement (Williams et al., 1997). The sibling intervention consisted of structured, educational, and support group sessions totaling 10 hours. Additionally, one 3-hour parent group was held simultaneously with one of the sibling sessions. The Knowledge of Illnesses Tests and the Sibling Perception Questionnaire were used to collect the data for this one-group pretest-posttest study. The results of the paired t-test analysis showed a significant increase in mean scores on the knowledge of illness measure after the intervention. Furthermore, consistent with the findings of Sahler and

Carpenter (1989), the study intervention showed positive effects on siblings of chronically ill children, based on the results of the Sibling Perception Questionnaire.

A later study (Williams, et al., 1999) was based on data collected from the families that participated in the pilot study described above. In addition to the pilot data, siblings completed Harter's Self Perception Profile for Children (1985) and the mood scale of the Sibling Perception Questionnaire. The mothers completed the FACES (Olson, Portner & Bell, 1978). An exploratory factor analysis was used to generate a causal model. Results showed significant path coefficients, indicating that positive maternal mood was associated with sibling perception of higher social support, which in turn was related to higher self-esteem and more positive sibling mood.

The majority of the aforementioned studies indicate that sibling adaptation was enhanced in families that had a greater degree of cohesiveness and social support systems; however, there does not seem to be evidence of a direct effect. This may, in part be related the fact that many studies on sibling adaptation have mixed findings suggesting both positive and negative results.

Family Typology and Sibling Appraisal

Family typology can foster resiliency in children through flexible structure, shared leadership, and mutual support. How children appraise an experience largely depends upon communication, open emotional expression and empathetic response, and collaborative problem solving skills among all family members (Marcus, 1999).

Vance et al. (1980) studied family variables that affect siblings of children with nephrotic syndrome. In a well-controlled study, families of children with nephrotic syndrome were closely matched with families of children without a chronic illness and

the two groups were compared in terms of psychosocial adaptation. The investigators found the frequency of serious problems experienced by the siblings to be much less than had been expected (Vance et al., 1980). However, nearly twice as many siblings of children with nephrotic syndrome reported not having enough friends and time to play as compared with siblings in the matched group. The school performance of the sibling group was significantly worse than the control group. Siblings of children with nephrotic syndrome had less feelings of security and social confidence than their matched peers. Vance et al. (1980) suggested that the effects of a chronic illness vary with the family's coping style.

Likewise, Taylor (1980) interviewed 25 siblings, ages 7-12 years, of children with asthma, cystic fibrosis and congenital cardiac defects to investigate the reaction to chronic illness. Increased feelings of isolation, deprivation, inferiority, or inadequate knowledge about the sibling's illness were found in two-thirds of the siblings, while other siblings did not appear to be affected. The increased amount of family time spent on medical care for the ill child and the sibling's decreased opportunity for play activities were described by the siblings as the most negative experiences. Spinetta and Deasy-Spinetta (1981) conducted a descriptive study of a convenience sample of 102 siblings, aged 3-18 years, to determine the effect of the family functioning on sibling appraisal. The authors found lower self-esteem, anxiety and depression in those siblings that perceived the family as experiencing conflict and less cohesion.

An exploratory, qualitative study by Harder and Bowditch (1982) noted that a family typology indicating an increased level of family cohesiveness led to a more positive appraisal of the illness experience. Birenbaum (1989) studied 61 siblings

between the ages of 4 to 17 years, all of whom were from families with a child in the terminal phase of cancer, to determine if increased cohesiveness and communication would foster a more positive appraisal of the illness and better coping as manifested by fewer behavioral problems and more social competence in siblings. Parent-sibling communication was positively related to sibling social competence and inversely related to behavior problems. The positive relationship between parent-child communication and social competence scores may reflect the sensitivity of the parents to the siblings needs.

Varnl, Katz, Colegrove and Dolgin (1996) utilized a risk and resiliency conceptual framework to investigate how family functioning was a predictor of adjustment for families with a child newly diagnosed with cancer. The family typologies that encompassed the traits of cohesion and expressiveness most consistently predicted positive psychological appraisal and social adjustment. Likewise, Horowitz and Kazak (1990) compared the siblings of children with cancer with a control group of siblings of children without cancer and concluded that family resiliency and cohesion were negatively related to behavior problems in siblings of the cancer patients as measured by interviews of all family members. To the contrary, in a five- year longitudinal study Breslau and Prabucki (1987) identified an increased risk of feelings of depression and isolation among the siblings, 11 years and older, of children with congenital disabilities and chronic illnesses living in a rigid and disengaged family structure. The siblings appeared to maintain high anxiety levels across the five- year study period and became more symptomatic relative to the control siblings.

Using structural equation modeling, Lavee, McCubbin, and Olson (1987) examined causal relationships among stressors and strains, marital adjustment, family well-being and family coherence. Coherence was found to be positively correlated to family well-being, indicating that families who are able to perceive problems as resolvable may be better able to adapt than families without this capability. The investigators also unexpectedly discovered that a positive correlation between a sense of coherence and family strain when marital adjustment was controlled for. This finding may suggest that the experience of overcoming demanding situations can enhance a family's sense of coherence.

Gallo and Szyclinski (2000) conducted a descriptive, correlational study to determine if differences exist in self-concept and satisfaction with family functioning among siblings of children with asthma, diabetes and siblings without a chronic illness. A non-probability sample of 135 siblings, aged 7-12 years, was recruited from clinics, physician offices and grammar schools in suburban Illinois. Data were collected using the Self-Perception Profile for Children (SPPC) (Harter, 1985) and the Family APGAR for Children (FAC) (Austin & Huberty, 1989). Using scores from the SPPC, data indicated siblings in the diabetes group scored lower than the siblings in the asthma group in four areas: Global Self-Worth, Social Acceptance, Scholastic Competence and Partnership. However, there were significant relationships between FAC total scores and SPPC scales. More specifically, siblings in the diabetes group rated several subscales on the SPPC higher when they reported more overall satisfaction with family functioning. The results imply that an open family environment in which siblings are encouraged to

talk and express their feelings may help promote a more positive appraisal to living with diabetes.

Other studies examined the relationships that a chronic illness has on family relationships, the effects of which may influence the sibling's appraisal of the illness experience. Ferrari (1984) compared siblings of children with type 1 diabetes and siblings of children with developmental delay with siblings of children without a chronic illness. Data from the parents indicated that siblings of children with type 1 diabetes had more behavior problems and more psychosomatic problems than either of the other groups. Wertlieb, Hauser and Jacobson (1986) examined how the attributes, values and behaviors that structure family life appear to influence the family's response to diabetes in The Health and Illness Study. The findings supported the notion that social and recreational family activities were associated with fewer adaptation problems as such activities fostered resiliency and a positive appraisal of the illness experience in the siblings. The preceding studies, relevant to family typology, further the understanding of how family structure affects the way sibling appraises the experience of living with a chronic illness in the family. However, the relationship between family typology, sibling appraisal and social support was not addressed in any of the studies above. The present study attempted to fill the gaps in the knowledge by examining how the above variables are interrelated.

Social Support and Sibling Appraisal

The effect of social support and sibling appraisal has been illustrated by studies relating to type 1 diabetes and as well other childhood chronic illnesses. The association between sibling relations and the psychological and illness-specific adaptation of children

with type 1 diabetes was examined by Hanson et al. (1992) in a study of 66 children with type 1 diabetes and their parents. Although the siblings did not participate in the data collection process, The Sibling Relationship Questionnaire (SRQ) (Furman & Buhrmester, 1985) assessed the child with diabetes' perception of the sibling relations. The findings suggest that sibling relationships with others, especially sibling conflict, were significantly related to the sibling's appraisal of the illness including low acceptance of the illness, and high levels of internalizing behaviors (Hanson et al., 1992). By definition, resilient families, like resilient individuals, have the ability to recover from adversity and adapt to change (Patterson, 1991). When the family system is the unit of analysis for assessing resiliency, the focus is on the family process, that is, the patterns of relationships connecting the members of the family system. From a family systems perspective, mutual causality is emphasized, therefore the resilient family is both a system that has adapted well to the chronic stress associated with living with a chronic illness, as well as a mediator of the sibling's own resilience. This is similar in approach to research conducted on family strengths (Whitchurch & Constantine; Stinnett, 1979, Mengel et al., 1992) and is especially reflected in the definition proposed by the Resiliency Model of Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993).

Management behaviors on the family level are those that have implications for the family unit as a whole as well as its individual members. Deatrick, Knafl and Walsh (1988) found that the parents of the children with osteogenesis imperfecta make explicit efforts to participate in some special events as a family unit. In their study of 15 parents of children with osteogenesis imperfecta, interviews revealed that parents

deliberately worked to create a more normalized family life by planning family social outings, as well as other family-centered activities.

The resilient family must generally achieve a balance between the illness demands and the family's normal developmental needs. The findings of a study of families with a child with cystic fibrosis suggest a relationship between parents taking time for themselves and for their relationship and improved health outcomes for the child (Patterson, McCubbin & Warwick, 1990). Maintaining a balance in the family system requires the family to be flexible enough to establish priorities that maintain the family's normalcy.

Garmezy, Masten and Tellegen (1984) conducted a study to identify the protective factors that promote resiliency and identified higher intelligence, quality of parenting, connection to other competent adults, internal locus of control and social skills as such factors. However, a later study examined the association between exposure to stress and various aspects of school-based competence and found that the relation of the exposure to stress and competence varied as a function of how the criteria of competence were constructed (Masten et al., 1988). The authors concluded that school-based competence alone does not seem to be a sufficient indicator of resilience. In this study, resilient youth were identified as those children who had experienced higher levels of adverse life events and were well adjusted and free of psychiatric disorders. Accordingly, resilient children are a subset of well-adjusted youth who have experienced adversity and adapted in a positive manner. A better understanding of resilient behaviors is a necessary precursor to target intervention programs designed to promote a more positive appraisal of the illness experience in siblings of children with chronic illnesses.

Fielding, Moore, Dewey, Ashley, McKendrick and Pinkerton (1985) investigated the psychological effect of chronic renal failure on the parents and the siblings in the family. Thirty-two patients attending the renal clinic at a children's hospital in Liverpool, England were included in the convenience sample. Self-report questionnaires were filled out by the patient, parents and the siblings. The Leeds Scale for the Self Assessment of Anxiety and Depression (Snaith, Bridge, & Hamilton, 1977), and the Malaise Inventory (Rutter, Tizzard & Whitmore, 1970) were filled out by the patients, and the Eysenck Personality Questionnaire (Eysenck & Eysenck, 1981) and the Family Relations Test (Bene & Anthony, 1978) were completed by the patient and siblings. The data showed that the children with the chronic illness and the siblings showed remarkable resilience in the face of serious and life-threatening disease. High levels of psychological distress were noted in some of the parents of children with renal disease with poor coping strategies, and families with positive coping strategies showed greater adaptation (Fielding, Moore, Dewey, Paula, McCormick & Pinkerton, 1985).

By creating social circumstances that differ from conventional norms, the presence of a chronic illness in the family may attenuate the family's relationship with the community. The family's appraisal of the situation as a negative event may cause the family to feel the need to protect the family's image. This, in turn, can lead to a disruption in the communication between family members. In a study of families of children with cystic fibrosis, Burton (1975) found that 53% of the mothers had never discussed the disease with the well child. Explanations given to the remaining 47% were simplistic and minimal. Burton (1975) also noted that the well children rarely asked questions relating to the disease or its treatment. The author interpreted this to be a

reflection of the children's need to protect their parents and the children's fear that the parents may lack the capacity to tolerate the illness and that their questions may precipitate a breakdown or rejection of themselves. Thus, siblings may avoid communication and keep their thoughts and feelings to themselves in effort to maintain the approval of significant adults. Conversely, Pineyard (1983) interviewed 6 female and 6 male siblings, aged 6-12 years, of children with myelomeningocele and their parents. The author found that the majority of siblings of children with myelomeningocele had an accurate understanding of the disease, and did not express any overwhelming worries or concerns. In addition, the siblings did not feel that play or peer activities were affected, nor were they concerned about parental time equality or their increased responsibility for chores.

In summary, data from the preceding studies yield promising empirical support for the hypothesis that parent-child relationships and sibling relationships represent interrelated and independent subsystems within the family and that both subsystems may influence the family's appraisal of type 1 diabetes. Adverse events such as the presence of a chronic illness in the family, in turn, may lead to psychological psychopathology or may be seen as a challenge to overcome. The recognition of predictors and interventions to promote a positive appraisal on life as well as positive coping behaviors might facilitate the prevention of psychological problems in siblings of children with type 1 diabetes.

Sibling Appraisal and Sibling Adaptation

The earliest studies of the sibling's adaptation to chronic illness focused on the childhood cancer experience. The early literature, written at a time when the child with

cancer nearly always died, dealt almost exclusively with the adaptation to the death of the child rather than on the adaptation to the illness itself. The early work of Cobb (1958), Furman (1964), and Binger et al. (1969) described the major stressors identified by families who face the crisis of a child's death. The data from these studies were gathered from the reports of the child's behavior based on the mothers' observations. Problems described by the parents included enuresis, headaches, poor school performance, school phobia, depression, severe separation anxiety, and persistent abdominal pain. According to Binger et al. (1969), some siblings complained about the parent's preoccupation with the sick child as a rejection of themselves and expressed guilt and fear. Modern cancer treatment, albeit very sophisticated, cannot guarantee a cure with every child, and therefore the sibling response to terminal cancer differs markedly from the response to other chronic non-fatal illnesses, such as type 1 diabetes.

Crain, Sussman and Weil (1966) emphasized the theoretical position that intra-family processes are more comprehensible when the family is viewed as a unity of interacting personalities in which the nature of each interaction affects the nature of each other member's reaction and the relationship existing between each of the members. The authors also stressed the fact that all illnesses do not have similar effects on children and other family members. The diagnostic criteria of an illness have implications and significance that differentiate it from other illnesses; hence, the sibling's appraisal of cancer may be expected to be different from that of diabetes. Nineteen children with type 1 diabetes and 16 siblings of children with diabetes were studied by the authors to examine the social and personality development of the child with the diabetes and the sibling with diabetes. The authors hypothesized that the child with diabetes will have a

poorer record of social-psychological functioning than the child without diabetes and the child with diabetes will have a closer relationship with the mother than the child without diabetes. Data were collected during home visits through observation and self-report questionnaires administered to both the mother and the child (Crain, Sussman & Weil, 1966). The first hypothesis was not supported based upon the conclusion that the child with diabetes performed neither significantly better or worse than the children in the sibling group. The second hypothesis was supported in that the mothers have a closer expressive relationship with the child with diabetes than with the well sibling. Such findings illustrate that the presence of a chronic illness may affect the family members quite differently, depending upon the nature of the variable and upon the nature of the family member's involvement with the disease. In addition, the greater the degree to which the new patterns of family functioning fit the child's appraisal of the situation, the better able the sibling will be able to adapt.

These early studies were instrumental in that they identified the behaviors of the siblings; however they are limited by methodological issues such as small sample size, reliance on case studies and anecdotal information, lack of comparison groups and by an almost exclusive reliance on the maternal ratings of sibling behavior. The findings of such studies, however, prompted research that focused directly on the sibling's own appraisal of a child with a chronic illness. As such, these studies point out the importance of studying the family as a collaborative unit of independent family members to capture data about structural and functional family variables related to living with a chronic illness in the family.

The presence of a chronic illness, such as type 1 diabetes, in the family, is a major life stressor that creates significant demands on the family system and may place a family and its members at risk for problems in adaptation (Patterson & McCubbin, 1983). Prolonged stress is known to cause psychological problems, as well as physiological changes that may lead to actual tissue damage or illness but coping strategies that are effective under a variety of stressful circumstances can serve to diminish the untoward effect of stress (Haggarty, 1986). A variety of coping strategies may be used by children to adapt to the presence of chronic illness in the family. Coping strategies, which are defined as learned, deliberate, and purposeful emotional and behavioral responses to stressors, are used to appraise the environment, respond to the environment or to change the environment. As coping strategies are learned behaviors, they can be acquired, changed, or eliminated (Walker, 1988). In addition, any explanation of coping strategies among children must be specific to the child's age, developmental level, cultural background and socioeconomic level.

While earlier investigators generally focused on siblings' psychological distress or deviant behaviors, the researchers in the 1980's began to measure adaptation and maladaptation rather than adjustment problems. Kramer (1981) was one of the first nurse researchers to identify both negative and positive outcomes of having a sibling with cancer. Eleven siblings of childhood cancer patients were interviewed using a semi-structured format. The results showed both positive and negative consequences of the illness. Possible coping efforts were identified when the siblings were asked what advice they would give other children in a similar situation. Negative consequences included anger, guilt and emotional stress while the positive responses included increased empathy

for parents, respect for the ill child, and improved self-concept. The siblings identified three factors they believed were critical in facilitating adaptation. First, these children reported that they needed information about the disease and treatment as well as the patient condition. Second, maintaining open and honest family communication was essential. Lastly, the siblings expressed a need to be involved in the child's experience with cancer.

Likewise, Iles (1979) conducted a pilot study of school-aged siblings of cancer patients to determine how the siblings perceive the cancer experience during the various phases of the illness. Data from the siblings were gathered during a taped 45 to 60 minute semi-structured interview in which open-ended questions encouraged verbalizations of the sibling's perception regarding family life during the current phase of the illness. The taped perceptions of the siblings elicited during the interviews and picture drawing sessions revealed themes of change, loss, and growth in human relations and self-concept.

Cairns et al. (1979) explored the adaptation of siblings to childhood malignancy in a study of 71 families. Using the Piers-Harris Children's Self-Concept Scale (Piers & Harris, 1969), the Bene-Anthony Family Relations Test (Bene & Anthony, 1978), and the Thematic Apperception Test (Murray, 1943), the researchers studied children with cancer and their siblings (N = 102). The study revealed that the siblings of children with cancer had significant anxiety, fear concerning their health and social isolation. Both siblings and cancer patients had negative body image scores. Although the siblings did not experience the bodily changes of the ill child (loss of weight, loss of hair and amputation), the child's illness had such a profound effect on them that the siblings

experienced an altered perception about their own health. In addition, the authors suggested that the long-term needs of the siblings might be slighted as parents focus on the needs of the ill child (Cairns et al., 1979).

Menke (1987) used a qualitative approach to study siblings, aged 6-12 years, of children with various chronic illnesses. The sample included the siblings of children with cancer (n = 20), cystic fibrosis (n=15), congenital heart disease (n=14), myelomeningocele (n=12) and burns (n=11). The siblings were asked questions regarding their concerns regarding the illness using semi-structured interviews. The majority of the siblings expressed worries about the child with the illness. The siblings of the children with myelomeningocele worried the most followed by the siblings of the children with cancer and cystic fibrosis. The authors suggested that the siblings do appear to understand the effects of having a chronic illness and have concerns for the ill child.

Sorenson (1990) conducted a qualitative study in attempt to identify and describe the day-to day coping responses to reported stressors in a sample of children without a chronic illness. The nonprobability sample was recruited by responses to letters describing the study, sent home with elementary school children. The sample included 32 subjects, 14 boys and 18 girls, from 20 families with an age range of 8-11 years. Two study instruments, the sentence completion list and the semi-structured daily journals, were completed by the children. The instruments were open-ended qualitative measures seeking subjective report to encourage individual perceptions. Twenty-one categories among four themes of cognitive, cognitive-behavioral, behavioral, and interpersonal coping responses emerged, beginning a taxonomy of children's coping responses. The

results of this study supported the work of Walker (1988); however, some new coping strategies emerged. Such categories included behavioral reframing, taking personal responsibility for one's behaviors, manipulation/deception, immobilization, and emotional horribilizing (Sorenson, 1990). The data support the fact that a child's perception of the situation can affect their choice of coping strategies. The choice of coping strategies can influence resilient behaviors that ultimately can influence the child's overall adaptation.

Gallo, Breitmayer, Knafl and Zoeller (1991) used a qualitative approach to investigate how sibling's view stigma in childhood chronic illness. Siblings who were nearest to the age of the child with the chronic illness and between the ages of 6-14 years, were asked to participate in a taped recorded interview focusing on the sibling's perception of the illness, their approach to management and the impact that the illness had on their own lives and the lives of their family. While all of the siblings acknowledged the ill child's chronic illness, one-third of the siblings minimized the ill child's differences by deemphasizing the differentness. According to the authors, minimizing the importance of the illness diverts attention from the potential stigma and creates a more comfortable situation for all. Most of the children did not report any major changes in their daily lives or peer relationships, many of them specified a variety of tasks that they helped the child with that they would not ordinarily do if the child did not have a chronic illness. The data from this study supported the conclusion that siblings exhibit compassion, tolerance, and empathy for the child with the chronic illness. This study also underscores the importance of the need for nurses to assess the siblings perception of the illness experience and not rely exclusively on the parent's view.

Adams, Peveler, Stein and Dunger (1991) investigated the psychological adaptation of siblings of children with type 1 diabetes at the John Radcliffe Hospital, Oxford, England. Thirty-one families with a child with type 1 diabetes and a sibling aged 8-18 years were recruited over a 6-month period. A semi-structured interview was used to assess the effects of living with diabetes in the family and included items related to knowledge and understanding of diabetes, involvement in its management, communication patterns with the family, health and health concerns, perceived impact on school lives, friendships and activities, and relationships and activities at home, relationships with the child with diabetes, ability to express feelings within the family and perceived differences in parental treatment of the child with diabetes. Although attitudes toward the child with diabetes were on the whole positive, the children were not free of feelings of emotional strain and envy. As a group, the siblings had raised levels of depression and lower levels of self-esteem. However, those siblings who felt free to discuss diabetes within their families reported lower levels of anxiety and their parents reported lower levels of behavioral problems. The authors suggested that the siblings' psychological adjustment could be enhanced by providing these children with appropriate information about diabetes, by making the parents more aware that the siblings might need special understanding and encouragement, and by allowing the children and parents the opportunity to express their negative feelings and concerns.

Evans, Stevens, Cushway and Houghton (1992) observed the effects that sibling knowledge had on the response to living with childhood cancer. The level of sibling knowledge about the disease was related to the level of sibling social competence but not to the prevalence of behavior problems. One-third of the siblings were not talking to

anyone about the illness experience and these children expressed the desire to have a support system (e.g., family members, health care professionals) to discuss their feelings with. The authors concluded that the sibling adaptation to cancer may not necessarily be pathological since so many siblings adapt well and that this adaptation may also be mediated by the level of social competence as well as the sibling's knowledge and perception of the illness (Evans, Stevens, Cushway & Houghton, 1992).

A later study, by Zeltzer et al. (1996), examined the overall health status, healthcare utilization, somatization, and health risk behaviors of siblings of children with cancer compared to these factors in matched controls in a as part of a larger multi-site study of siblings emotional, academic, and social adaptation to childhood chronic illness. The findings indicated that the siblings of children with a chronic illness who appraise the illness experience as negative are more likely to be at risk for emotional, behavioral and health-related problems.

Sloper and White (1996) investigated the psychological adaptation of siblings of children with cancer by examining the variables in family life including social support and family resources that effect adaptation to a chronic illness. The Sibling Social Support Scale for Children (SSSC) instrument was used to assess the child's perception of the situation as related to the degree of support from parents, teachers, close friends and classmates. The sibling's perception of their experiences in relation to the illness was assessed using the Sibling Perception Questionnaire (Carpenter & Sahler, 1991) and the sibling's coping strategies were assessed using the KIDCOPE Scale (Spirito et al., 1988). The results of the study demonstrated that problems in adaptation were correlated to the degree of disruption in family life, the resources available to the sibling and the

family, and the family's appraisal of the negative interpersonal effects of disease on their lives.

The studies on sibling appraisal identify several issues that may effect sibling adaptation to the illness. The results of the above studies highlight the following issues: the absence of a one-to-one correspondence between the presence of chronic illness in a child and psychological maladaptation in the sibling; sibling maladaptation is selective and varies with the outcome measure employed; and chronic illness is a stressor which, in interaction with other factors, may contribute to the increased risk of psychological maladaptation for some siblings. However, the studies of the psychological adaptation of siblings have increased in methodological sophistication over the years. The import of the early sibling research was limited by small sample sizes, subjective versus objective methodology and the lack of a control group. It is now recognized that research on sibling adaptation is an extremely sophisticated endeavor that requires the researcher to overcome difficulties related to the control of variables expected to influence adaptation, the choice of outcome measures, and the development of conceptual frameworks to guide the hypotheses, especially those that consider family systems influence.

Such dilemmas require the investigator to carefully consider the choice of specific outcome measures in light of the research aims and psychometric measures of the instruments. The inconsistencies in the aforementioned studies on sibling adaptation may well be contributed to the measures employed as measures of true psychopathology may yield very different findings than instruments that measure developmental competencies such as self-esteem and coping strategies. Additionally, because the manner in which the relationships and perceptions of family members affect sibling adaptation is still poorly

understood, advanced statistical techniques such as path analysis and structural equation modeling may be helpful as they allow the investigator to determine the relationships of all the variables in the model as they relate to one another.

Appraisal as a Mediating Variable between Social Support and Sibling Adaptation

Many stressors are only as stressful as the child perceives them to be; thus, the cognitive appraisal of a stressor's potential threat or harm is an important part of the coping process that mediates the response. Similarly, there is also a cognitive appraisal of one's resources for mastery of the stressor that also affect the child's adaptation to the stressor. Perhaps it is the child who lacks effective coping strategies who is most vulnerable to maladaptation, rather than the child who experiences the greatest amount of stressors.

Anderson and Auslander (1980) conducted a literature review on the evolution of the family systems model in research on diabetes management and the family. The researchers found that although the pediatric patient had traditionally been seen as a passive receptor of the parental influences, more recent research has broadened this perspective by focusing on the family as an interactive unit. As such, this focus of the family as a system emphasizes the importance of including the siblings in the course of diagnosis and treatment of their brother or sister's illness.

Caldwell and Pinchert (1985) applied the systems theory approach to study the family functioning in the family with a child with type 1 diabetes. The purpose of the study was to examine relationships between patterns of communication and outcome variables that, according to family system theory, might be influenced by the way family

members communicate with one another. The authors concluded that no significant relationships were found between family functioning, sibling knowledge, sibling appraisal of the illness experience and self-concept. Family communication was significantly correlated with the total family stress scores. The authors concluded that communicative functioning affected family stress that in turn affects the family system as a whole (Caldwell & Pichert, 1985).

In an interventional time-series repeated measures design study, Craft, Lakin, Opplinger, Clancy and Vanderlinden (1990) observed self-reported improvement in family functioning and increased sibling self-confidence in families with a child with a chronic illness. A significant difference was noted in the mobility of the child with cerebral palsy after the completion of the intervention involving physical and occupational therapy. Additionally, the siblings gained an increased sense of importance and learned the importance of their interactions to both the child's and family's well-being. The researchers concluded that siblings may be important teachers, role models, and agents of change in families that have a child with a chronic illness (Craft, Lakin, Opplinger, Clancy & Vanderlinden, 1990).

Gardner (1998) described a comparison of children with type 1 diabetes with two control groups including a group with the sibling nearest to them in age, and a group with peers matched for gender and age. The results were analyzed to provide data on whether the siblings appraised difficulties in their life and the degree to which these perceptions were related to diabetes. The data indicated significantly higher scores for the children with the diabetes on the parent scales on factors such as hyperactivity, psychosomatic disorders and restlessness/disorganization, in comparison to their siblings but not their

peers. The authors concluded that very few children with diabetes and their siblings are without adaptation problems. For both the children with diabetes and the siblings, problematic issues included identity difficulties, autonomy difficulties and an increased perception of family stress.

A qualitative study was conducted by Walker (1988) to identify and describe the behavioral and coping strategies used by siblings of pediatric cancer patients using the conceptual framework of coping strategies proposed by Lazarus and Folkman (1984). Subjects were selected from families of pediatric oncology patients being treated at a regional children's hospital who had one or more siblings aged 7-11 years. The families were in one of the following three treatment phases: induction, remission or in relapse. The data from the parents were obtained through open-ended interviews designed to identify stressful issues for the family in general and then to focus on the siblings. The siblings were interviewed on two separate occasions. Each interview was individualized through the use of puppet play and drawings, to accommodate for the child's verbal ability, needs, and the developmental level. During the second interview, the children were asked to respond to cartoon scenes, sentence completion, and direct questions. Content analysis was used to analyze the data and the three major themes of loss, fear of death, and change emerged. The information was used to develop a taxonomy of cognitive and behavioral coping efforts describing the sibling response to childhood chronic illness. Two domains of coping strategies, cognitive and behavioral, were identified. Within the cognitive domain the following coping strategies were used: emotional expression, wishful thinking, empathy, avoidance/denial, regression, talking with others, and being with others. Within the behavioral domain the siblings relied on

the following actions: playing, music, quiet activities, exercise, acting out, somatization, seeking solace in a special place, family contact, social contact, and temporary escape

Semi-structured interviews were used to assess the sibling's appraisal of the illness.

Within the cognitive domain the following coping strategies were used: emotional expression, wishful thinking, empathy, avoidance/denial, regression, talking with others, and being with others. Within the behavioral domain the siblings relied on the following actions: playing, music, quiet activities, exercise, acting out, somatization, seeking solace in a special place, family contact, social contact, and temporary escape.

Cohen, Freidrich, Jaworski, Copeland & Pendergrass (1995) studied the adaptation of siblings of children with cancer with a sample of 129 siblings, aged 4-16 years. The mothers completed the Achenbach Childhood Behavior Checklist (1991) in order to assess how the siblings of children with cancer behaved as compared to the proportion expected under normal distribution. The authors noted that a significantly higher proportion of the siblings scored two standard deviations above the mean for internalizing and externalizing behaviors on the Childhood Behavior Checklist.

Taylor, Fuggle and Charman (2001) investigated the adaptation of siblings in relation to their perceptions about their brother's or sister's chronic illness, to their mother's awareness of the attitudes and perceptions, and three other maternal variables (maternal stress, maternal social support, and the amount of care necessary to manage the child's chronic illness). The majority of the siblings did not seem to have adaptation problems, however, the sample had slightly increased rates of emotional problems when compared with the norm for the general population. The mothers assessed the siblings as having more negative perceptions than did the siblings themselves. A multiple regression

analysis indicated that better sibling adjustment was associated with an increased maternal awareness of the attitudes and perceptions of the siblings.

No studies could be found that tested the relationship between social support, family typology, sibling appraisal and adaptation in siblings of children with type 1 diabetes. Studies of the coping strategies used by children who adapt well may reveal useful information for health promotion, particularly for children at risk. The children have a need for information. They generally have heard of the chronic illness but may find it an ominous unknown. The siblings need to be involved with the child's care and to be kept informed about the status of the illness. It is evident from the research thus far that siblings of children with a chronic illness can articulate private perceptions of stress-coping experiences into their lives. Therefore the researcher must consider the child's knowledge base, unique reaction to of the stressors and value their specific perception of reality. It will then be possible to plan intervention studies that address the individual's perspective, in effort to match the interventions with the child's own understanding of the chronic illness, appraisal of stressors and choice of coping strategies.

Conclusions

Overall, research into the adaptation of siblings of children with type 1 diabetes suggested that these children are different from their peers; however, the data recount discrepant results. The current literature proposed that such children may be at risk for more behavioral problems, psychosomatic problems and reduced self-esteem, while other siblings may show greater social behavior and sense of altruism. These discrepancies raise a major issue of interpretation; do the results actually reflect such differences in adjustment or are they the result of a perceptual bias in the parents? Perhaps, when comparing children with type 1 diabetes to their siblings without type 1 diabetes, it may be that parents tend to overestimate the problems of the former over the latter. Gardner (1998) suggested that a plausible explanation may be that at home the children with type 1 diabetes are labeled as the “problem children” and the adaptation response of the sibling is one of being the “problem-free children.” Another explanation for the contradictions may be due to the differences in who completes the questionnaires; for example, the parents, teachers or siblings. Each may have a different perspective of their behavior. Additionally, many children behave differently in the home setting than in the school setting. However, these differences in perspective may not necessarily be accountable for the discrepant results. In fact the theory of symbolic interactionism is based upon the assumption that individuals act differently based on their perception of the relevant factors in a given situation. Hence, the challenge rests with conceptualizing the sibling adaptation to chronic illness within a family systems model that takes into account the individual perceptions of the stressors faced by a family adapting to a chronic illness. Accordingly, the method of data analysis should provide a way to explain the

relationships between key variables that may explain this phenomenon of sibling adaptation such as social support, family typology, and sibling appraisal.

While considerable research has focused on the siblings of children with cancer, asthma and cystic fibrosis, mostly using small sample sizes, the studies describing the sibling response to type 1 diabetes are sparse. This disease differs from most other chronic illnesses as the characteristics of the family members play a large role in the management of diabetes. How the family is structured, its beliefs and problem-solving skills, and the patterns of interaction have been shown either to enhance the management of diabetes or exacerbate the stressors associated with the disease (Fisher et al., 1998). The way in which the family manages the chronic illness affects not only the patient's health, but the other family members as well. Accordingly, the siblings of children with type 1 diabetes stand out as a population at risk deserving of attention in research as well as in clinical practice endeavors.

The findings concerning sibling adaptation to type 1 diabetes indicated that the effects are much more complex than originally thought and require a comprehensive conceptual framework which considers family system influences such as The Resiliency Model of Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993). The results of previous studies have been discrepant because the majority of these studies have been guided by a deficit-centered framework that concentrates on the measurement of sibling psychopathology through the use of child behavior problem checklists. However, these instruments did not take the child's competencies into account. The measurement of competencies might help to predict which children will reasonably adjust to their sibling's illness. Furthermore, the study of sibling competencies might help to

develop interventions to help those siblings who do have difficulty with adapting to a chronic illness in the family.

The dearth of knowledge in this field becomes especially problematic when the goal of health care professionals working with children with type 1 diabetes is to deliver family centered care. To date, there have not been any studies which utilized The Resiliency Model of Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993) as a conceptual framework to study the siblings of children with type 1 diabetes, and unfortunately the majority of researchers have studied the negative impact on well siblings or their potential for maladjustment. Deficit approaches to the development of sibling response theory need to be balanced by creating theory that includes the potential benefits and advantages of the experience of living with a child with type 1 diabetes. It will never be enough to simply identify resiliency factors in siblings; it is important to know how to create these resiliency factors through encouraging effective coping strategies and problem-solving behaviors.

Therefore, the present study focused on the adaptation of the siblings individually and the family collectively utilizing The Resiliency Model of Stress, Adjustment and Adaptation to study the adaptation of siblings to living with type 1 diabetes within the family. Highly structured theory guided research can be potent in the development and implementation of hospital and community- based programs designed to promote coping strategies and behavioral patterns that enhance the sibling adaptation to living with the stressors associated with type 1 diabetes.

CHAPTER 3: RESEARCH METHODS

Research Design

This study was a descriptive exploratory study conducted with families of children with type 1 diabetes. The study aimed to investigate the factors related to variation in adaptation for the siblings of children with type 1 diabetes, answering the following research questions:

1. What are the coping strategies used by siblings of children with type 1 diabetes as measured by the Schoolager's Coping Strategy Strategies Inventory (SCSI) ?
2. What is the sibling's appraisal of living with type 1 diabetes in the family as measured by the knowledge, perception and mood subscales of the Sibling Perception Questionnaire (SPQ)?
3. How well do the siblings of children with type 1 diabetes adapt to living with type 1 diabetes in the family as measured by the Children's Depression Inventory (CDI)?
4. Using structural equation modeling, what are the relationships among family typology as measured by the adaptability and cohesion subscales of the Family Adaptability and Cohesion Scale (FACES II) and the cohesion subscale of the Coping Health Inventory for parents (CHIP), social support and resistance resources as measured by the resource subscale of the Family Inventory of Resources for Management (FIRM) and the social support and communication subscales of (CHIP), sibling appraisal as measured by the perception and mood subscales of the Sibling Perception Questionnaire (SPQ)

and the Children's Depression Inventory (CDI) and the sibling adaptation to living with type 1 diabetes in the family as measured by the frequency and efficacy subscales of the Schoolager's Coping Strategy Strategies Inventory (SCSI), the knowledge subscale of the Sibling Perception Questionnaire (SPQ) and the global subscale of the Self-Perception Profile for Children (SPPC)?

Sample

The number of subjects was 128 siblings, exceeding the 123 subjects required to detect effect using structural equation modeling. Power is an important consideration in structural equation modeling; however evaluating how much power is available in a given structural equation model is not a simple or straightforward matter (Norris, 1997). MacCallum, Browne and Sugarara (1996) propose an approach for calculating power and minimum sample size for the test of close fit for a structural equations model based on the root-mean-square error of approximation (RMSEA). They also provide Statistical Analysis (SAS7) programs for computing power and minimal sample size. Minimal sample size depends primarily on the degrees of freedom $d = p(p+1)/2 - q$ where p is the number of manifest variables and q is the number of parameters in the model. For the proposed model used in the study, $p = 13$ and $q = 18$, and so there were $d = 13(14)/2 - 18 = 73$ degrees of freedom. The minimal sample size also depends on the desired significance level α , the desired power, and two settings ϵ_0 and ϵ_a for the model discrepancy ϵ per degree of freedom (a function of RMSEA). The first setting ϵ_0 measures what it means for the model to have a close fit while the second setting ϵ_a measures the level of not close fit at which the desired power is to be achieved. MacCallum, Browne and Sugarara (1996) recommend the settings $\epsilon_0 = 0.05$ and $\epsilon_a = 0.08$. The minimal sample size for models

with 73 degrees of freedom that is required to have power of 0.80 at $\varepsilon_a=0.08$ for the test of close fit, testing whether ε is within $\varepsilon_0=0.05$, was computed from the appropriate program to be 116 observations.

Description of Population

A convenience sample of 128 siblings of children with type 1 diabetes (ages 8-14 years) and one parent from each family were selected as participants for the study. The participants were recruited mainly from the regional pediatric diabetes service at Yale-New Haven Medical Center through referral by the staff of the hospital. A notice describing the study was all posted at the clinic asking interested families to call the primary researcher. Children aged 8 to 14 years, with English as a primary language, and who live with a sibling with type 1 diabetes were included in the study. Every attempt was made to enroll subjects of all minority groups. The selection criteria were as follows:

Inclusion Criteria

1. The sibling's age was 8 years to 14 years (on the last birthday);
2. The sibling shared the same household as the child with type 1 diabetes;
3. The sibling had no existing serious chronic medical disorder (e.g. cancer, juvenile rheumatoid arthritis);
4. The sibling and parent(s) spoke, understood and could read English, and could comprehend the instruments;
5. The family consisted of at least one parent, a child with type 1 diabetes and at least one sibling. If there were more than one sibling that qualified for the study, the sibling closest in age to the child with diabetes was included in the study.

Exclusion criteria

1. The sibling did not speak or did not understand English, and would not be able to understand the instruments;
2. The sibling had an existing serious chronic medical disorder (e.g. cancer, juvenile rheumatoid arthritis);
3. The sibling had a serious psychological, emotional or behavior disorder (e.g. attention deficit hyperactivity disorder, bipolar disorder);
4. The sibling had been kept back more than one year in school because of academic performance.

Operational Definitions

The operational definition of “family” for this study was any primary adult caregiver (mother, father, stepparent) and any child living in the same household (brother, sister, stepbrother or stepsister), related by blood or adoption. The “family” does not include any extended family members, even though they may share the same dwelling. The data were collected at the home of the family and the primary researcher was the sole data collector. The siblings completed the questionnaires without the influence of their parents or any other adult. The parent questionnaires were completed by either the mother or the father. However, in all but three cases in which the parents were divorced and the father assumed the primary care taking for the management of the diabetes, the mothers completed the instruments. To assure that there were no gender specific differences between males and females that would affect the results of the data on the parent questionnaires, t-tests were subsequently performed to compare the

responses of the mothers to those of the fathers. There were no significant gender differences on any of the subscales of any of the instruments except for the cohesion of FACES. Therefore, data collected from both mother and the father were included in the final data analysis. Data comparing the responses for mothers and fathers are presented in Table 1.

Table 1

Comparison of Parent Instruments based on Gender

	t	df	Sig. (2-tailed)	Mean Difference
CHIP (cohesion)	.694	125	.489	2.52
CHIP (social support)	1.08	125	.281	5.11
CHIP (communication)	.801	125	.425	1.49
FIRM (resources)	-1.41	125	.160	-2.17
FACES (adaptability)	-.221	125	.825	.889
FACES (cohesion)	-2.30	125	.023	-11.0

The parents were asked to leave the room while the sibling completed the data collection instruments so that the child had some privacy to fill out the forms. The researcher remained with the siblings as they completed the forms to help with clarification of the instruments or with reading comprehension. The researcher explained to the parents that some children do not talk as openly with the parents present and having the parents leave the room may encourage the child to speak more openly. The parents were assured that the parents would be immediately notified should the response to any question be suggestive of depression or any other psychopathology and the

inpatient social worker on the inpatient clinical research floor of the Yale New Haven Children's Hospital would be notified should there be any need for urgent psychological care.

Setting

The study was conducted at the Yale-New Haven Medical Center. The Pediatric Outpatient Diabetes Service at Yale provides care to more than 900 children and adolescents. The patient population served is approximately 80% white non-Hispanic, 10% Hispanic, and 10% Black, as is the distribution of type 1 diabetes in the northeast United States. The population is equally divided by gender. Siblings of children with type 1 diabetes who are cared for in other area hospitals were also eligible for the study providing they met the inclusion criteria and did not violate the exclusion criteria.

Data Collection Instruments

Demographic information

The demographic data sheet was used to collect information regarding race, socioeconomic status, and religious affiliation. Parents were asked to provide information on demographic form including the age of parents, age of child and sibling(s), educational level of parents and sibling, occupation of parents', socioeconomic level of the family, sex of child, race of child, age of the child at the time of diagnosis of sibling's illness, and number of months since sibling's diagnosis. The demographic data form also included information specific to the sibling such as birth date, birth order, grade in school, and health status.

Parent Instruments

The Coping Health Inventory for Parents (CHIP). The CHIP (McCubbin, McCubbin, Nevin & Cauble, 1983) was developed to assess parents' appraisal of their coping responses to the management of family life when they have a child member who is seriously and/or chronically ill. CHIP was administered in order to determine what behaviors were chosen by parents of children with a chronic illness to cope with raising the child with a chronic illness and if these behaviors were found to be helpful. In order to describe or predict how a family adapts under a chronic stress situation, the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993) calls for information to determine if survivorship is underscored through coping rather than hardship (McCubbin, McCubbin, Patterson, Cauble, Wilson & Warwick, 1983).

The CHIP is a 45-item checklist containing three subscales: (1) family integration, cooperation and an optimistic definition of the situation; (2) maintaining social support, self esteem and psychological stability; and (3) understanding the health care situation through communication with other parents and with the health care team. This tool was initially developed, validated and utilized with parents of children with cystic fibrosis, and has been used in multiple studies of children with chronic illnesses. The reported Cronbach alpha values in the original studies were 0.79, 0.79, and 0.71. The Cronbach alpha values for the above subscales for the present study were respectively 0.74, 0.78 and 0.68. The criterion validity of the instrument was measured using the Family Environment Scale (FES) and several indices of childrens' health status comparing children with and without chronic illness. Construct validity was assessed using a factor analysis. The results indicated three factors that were rotated to a final solution using the

Varimax criterion. These three factors were designated as coping patterns and represent 71.1% of the variance. The first coping pattern is called Family Integration, Co-Operation and an Optimistic Definition of the Situation, the second coping pattern is called Maintaining Social Support, Self Esteem and Psychological Stability and the third coping pattern is called Understanding the Health Care Situation through Communication with other Parents and Consultation with the Health Care Team. The CHIP is written at the 6th grade reading level.

A total coping score is obtained by summing the number circled by the parent (0= Not Helpful, 1= Minimally Helpful, 2 = Moderately Helpful, and 3 = Extremely Helpful). Subscale scores are obtained by summing the number circled by the parent for the items in each subscale.

The scores from the Family Integration, Co-Operation and an Optimistic Definition of the Situation subscales were included in the structural equation model as one indicator of the latent construct of family typology. The scores from the Maintaining Social Support, Self Esteem and Psychological Stability subscale (critical indicator of support) and from the Understanding the Health Care Situation through Communication with other Parents and Consultation with the Health Care Team (critical indicator of communication) were used as two critical indicators of the latent construct of social support in the hypothesized structural equation model.

Family Adaptability and Cohesion Evaluation Scales (FACES II). FACES II (Olson, Portner & Bell, 1978) was used to assess family cohesion and family adaptability. The instrument has the ability to discriminate between functional and dysfunctional families around these two dimensions of family functioning likely to be affected by type

1 diabetes (Northam, Anderson, Adler, Werther & Warne, 1996). FACES II is a 30-item self-report questionnaire with a 16-item scale for cohesion and a 14-item scale for adaptability. The three central dimensions of family behavior (cohesion, adaptability, and communication) were derived from family systems theory literature. These are three primary dimensions integrated in the Circumplex Model as formulated by Olson, Russell and Sprenkle (1989). Cohesion is defined as the emotional bonding members have toward one another and the autonomy that a person has in the family structure. The cohesion scale has four levels: disengaged (very low), separated (low to moderate), connected (moderate to high), and enmeshed (very high). Within the Circumplex Model, specific concepts are used to diagnose and measure the cohesion dimension including emotional bonding, boundaries, coalition, time, space, friends, decision-making, interests and recreation. Adaptability is defined as the ability of the family system to change its power structure, roles and rules in response to situational and developmental stress. Specific variables used to diagnose and measure the adaptability concept include family power, negotiation style, role relationships and relationship rules (Olson, Portner & Bell, 1978). The adaptability dimension also has four levels: rigid (very low), structured (low to moderate), flexible (moderate to high) and chaotic (very high). For both cohesion and adaptability, the balanced levels (separated / connected and flexible / structured) are hypothesized to be most conducive for healthy family functioning and while the extreme levels (disengaged / enmeshed and rigid / chaotic) are generally thought of as being more problematic for families over time. Communication is the third dimension and it facilitates movement on the other two dimensions.

Respondents are asked to answer how frequently the described behavior occurs in the family on a scale from 1 (almost never) to 5 (almost always). Subjects rate statements such as “Family members feel very close to each other” (cohesion) and “Rules change in our family” (adaptability) on the one to five scale. Scores are obtained for both the cohesion and adaptability subscales (some items are reversed) to obtain total cohesion and adaptability scores. Under normal circumstances, a high total score would be indicative of a cohesive or adaptable family. The Family Type score is obtained by adding together the cohesion and adaptability score and dividing the total score by two. The alpha coefficient is 0.87 for cohesion, 0.78 for adaptability, and 0.90 for the total instrument (Olson, McCubbin, Barnes, Larsen, Muxen, & Wilson, 1983). In the present study, the alpha coefficient for the cohesion subscale was 0.76, for the adaptability subscale 0.77 and 0.83 for the total instrument. The FACES II is written at the 6th grade reading level.

The scores on both the adaptability and cohesion subscales were used as two critical indicators of the latent construct of family typology in the hypothesized structural equation model. Data from the communication subscale were collected and recorded but not included in the data analysis for the present study.

The Family Inventory of Resources for Management (FIRM). The FIRM (McCubbin, Comeau, & Harkins, 1981) measures the family’s social-psychological, community, and financial resources along personal, family system, and community dimensions. The selection of items for FIRM was influenced by literature and theory in three areas including personal resources, family system resources and social support. Personal resources refer to a broad range of resources, qualities and characteristics of

family members, which are available to individual family members in need. These resources include economic well-being; education and psychological attributes. Family system resources encompass primarily the concepts identified by Reuben Hill (1958) based on his work with families in crisis. The family system resources include cohesion, managerial ability and problem solving ability. Social support includes information exchanged between people, that provides emotional support; esteem support and network support. Social support from within the family, as well as from the extended family friends, neighbors, co-workers and community, is a dimension of resources particularly important for managing stress and for adaptation.

The instrument is written on a 6th grade reading level has a total of 69 items and has five subscales including Family Strengths I: Esteem/Communication which reflects family esteem, communication, mutual assistance, optimism and problem solving ability (Cronbach's alpha of 0.85); Family Strengths II: Mastery and Health, which includes a sense of mastery, mutuality, and physical and emotional health (Cronbach's alpha of 0.85); Extended Family Social Support, or help and support given to and received from relatives outside the nuclear family (Cronbach's alpha of 0.62); Financial Well-Being, or perceived financial efficacy (Cronbach's alpha of 0.85); and Resource Strains, or difficulty in acquiring or maintaining resources (Cronbach's alpha of 0.86). Content validity of the instrument is 0.79. The Cronbach's alpha for the one subscale used in the present study, the resource subscale, was 0.78. Concurrent validity for the FIRM subscales were assessed by comparing the FIRM subscales and the Family Environment Scale (FES) (Moos & Moos, 1986). There are significant positive correlations between the FIRM scales and the FES dimensions of cohesion, expressiveness and organization,

and negative correlations between family conflict and the four FIRM scales. According to McCubbin and McCubbin (1987) these associations between family resources and desirable family functioning provide support for the validity of FIRM. Test-retest validity of the instrument was not reported.

The FIRM is scored by summing the values of all the responses (Not at all =0, Minimally =1, Moderately =2, and Very Well =3). However for 30 of the 69 items the values must be reversed to ensure that all items are weighted in the same positive direction for both the analysis and the interpretation of the results. Two subscales, Sources of Financial Support and Social Desirability, were added to give additional information. Since these scales are not considered major subscales of FIRM they are not included in the data analysis. The total score on the Resource subscale of the FIRM was used as one critical indicator of the latent variable of Social Support in the hypothesized structural equation model.

Sibling Instruments

Sibling Perception Questionnaire (SPQ). The Sibling Perception Questionnaire (Carpenter & Sahler, 1990) is a 23-item scale using a five-point Likert Scale type response format. The instrument assesses a siblings' reaction to chronic illness on four dimensions: interpersonal interactions and relationships (nine items, e.g. "I wish my parents would spend less time with my brother/sister"; intrapersonal, how siblings perceive the illness to affect themselves (seven items, e.g. "I feel sad about my brother/sister's diabetes); communication (four items, e. g. "I can talk to my parents about my brother/sister's diabetes"); and fear of the disease (three items, e.g. "I worry that I can catch cancer from my brother/sister"). There are also six questions that require

the sibling to report reasons why they feel mad, afraid or sad and what they do about these feelings. Questionnaire items were derived from a selection of items written in consultation with several siblings as well as pediatric oncology professionals from medicine, nursing and social work. Three primary content domains were assessed including knowledge about the disease, perception of how the illness experience has an impact on the sibling, family relationships, and non-family relationships; and mood states.

Higher scores indicate more negative perceptions, except with regards to the dimension of communication in which a higher score indicates more communication. Carpenter and Sahler (1990) report internal consistencies of the scales ranging from 0.65 to 0.86. The internal consistencies for the present study were an alpha coefficient of 0.66 for the mood subscale, 0.76 for the knowledge subscale and 0.80 for the perception subscale. Although the items were designed specifically for siblings of children with cancer, written permission was obtained from Dr. Sahler (December, 28, 2000) to revise the items to be used for siblings of children with type 1 diabetes and the instrument was pretested in the pilot study. Since the siblings understood the format and content of the instrument, the instrument was included in the study.

The scores from the perception and mood subscales of the SPQ were used in the hypothesized structural equation model as two of the critical indicators of the latent construct of sibling appraisal and the knowledge subscale was used as one indicator of the latent construct of sibling adaptation.

Schoolagers Coping Strategies Inventory (SCSI). The SCSI (Ryan-Wenger, 1990) is a self-report, 26 item, instrument which measures the type, frequency, and

effectiveness of coping strategies used during a personally defined stressful event. Each coping strategy is rated for the frequency and effectiveness on a scale of 0 to 3. The scores on the 26 items are summed to determine a Frequency Score, ranging from 0 to 78; and an Effectiveness Score, also ranging from 0 to 78. Higher scores are indicative of a greater repertoire and effectiveness of coping strategies. A Cronbach's alpha of 0.76 for the Frequency Scale and 0.77 for the Effectiveness Scale provide evidence of the internal consistency of the instrument. The internal consistency for the present study was a Cronbach's alpha of 0.71 for the Frequency Scale and 0.73 for the Effectiveness Scale. Test-retest reliabilities of the Frequency Scale ($r=0.73$) and the Effectiveness Scale ($r=0.82$) were calculated to provide a measurement of stability. Content validity of the SCSI was determined by a panel of experts in child development. Content validity was also supported by the method in which the instrument was developed. Items were generated through the interviews of school age children. This methodology assured that the coping strategies were developed from a child's perspective rather than from adult inferences as to how a child copes with a stressor. Construct validity for the SCSI was supported by the known groups technique. Significantly lower coping scores among children with symptoms of stress as compared with children without symptoms of stress suggest that this instrument does adequately measure the concept of coping strategies in school age children (Ryan-Wenger, 1990). Divergent validity was demonstrated by low correlations in the scores between the SCSI and other instruments that measure the similar but different concepts of stressors and self-esteem. The scale is written on a 1st grade reading level.

Data collection can be done in a classroom setting, or individually. It is helpful if the investigator reads the items to the eight and nine year olds while older children catch on quickly and can usually complete the questionnaire on their own. To score the SCSL, the responses to the questions are given a numerical value. The values for the Frequency Scale are: 0 = Never, 1 = Once in a while, 2 = A lot and 3 = Most of the time and the values for the Effectiveness Scale are 0 = Never do it, 1 = Does not help, 2 = Helps a little and 3 = Helps a lot. The Frequency Scale score is the sum of children's responses on all 26 items. The number of coping strategies used equals the total number of items $n = 26$, minus the number of items with a response of 0 (never). The Effectiveness Scale score is the sum of the children's responses on all 26 items. The Total Coping Score (sum of the Frequency Scale and Effectiveness Scale) was initially intended to reflect the theoretical construct of coping which should encompass not only the frequency with which coping strategies are used, but how effective they are perceived to be. The author no longer recommends the calculation of a Total Coping Score because the empirical meaning of this score has been difficult to explain and apply to practice. According to Ryan-Wenger (1990), there is no assumption that one type of strategy is more adaptive or effective than another as the scores purely reflect the children's perceptions about their individual coping resources and abilities to cope with stressors.

The scores from the Frequency Scale and the scores of the Effectiveness Scale were used as two of the critical indicators of the latent construct of sibling adaptation the hypothesized structural equation model.

Self-Perception Profile for Children (SPPC). The SPPC (Harter, 1985) is a 36-item scale used to assess the schoolagers' perception of his or her abilities. The scale

represents a revision of the Perceived Competence Scale for Children developed by Harter (1979, 1982). The original scale was designed to tap children's domain-specific judgments of their competence as well as a global perception of their worth or esteem as a person. The scale tapped three competence domains, cognitive competence, social competence, athletic competence, as well as one's sense of global self-esteem or self-worth (Harter, 1985). The original scale focused primarily on children's judgments of competence. The revised instrument broadened the conceptualization of self-esteem to include items relating to self-adequacy as well as competence. The revised instrument consists of six subscales describing five specific domains of practice (scholastic competence, social acceptance, athletic competence, physical appearance, and behavioral conduct) and global self-worth. In order to reflect its current content the scale had been renamed as the Self-Perception Profile for Children. The new title reflects the idea that the scale is designed to measure children's perception of themselves, and the term "profile" emphasizes the fact that the examination of differences in a child's score across various domains of his/her life provides the richest and most accurate picture of one's self-concept (Harter, 1985).

As in the earlier version of the SPPC, each item describes two different groups of children (e.g. children who are often unhappy with themselves and versus children who are generally happy with themselves). The child is first asked to state which child he or she is most like. Having made this decision, the child is then asked to decide whether the description is "sort of true" or "really true" for him or her. The items in the SPPC are scored four, three, two or one, where four represents the most positive self-judgment and one represents the most negative self-judgment. Items within each subscale are counter-

balanced such that three items are worded with the most adequate statements on the left and three items are worded with the most adequate items on the right. Items from each of the subscales are calculated together, resulting in a total of six subscale scores that will define a given child's profile.

Higher scores on the SPPC indicate a higher perceived competence. The SPPC and the subscales have adequate internal consistency reliability (0.71- 0.85). The Behavioral Conduct Scale shows somewhat lower reliabilities. One Behavioral Conduct item (#35, kinder to others) consistently attenuated the reliability across subscales and was therefore replaced by a new item specifically focusing on behavior. In addition, one Social Acceptance item (#14, hard to like) and one Global Self-Worth item (#6, mad at self) had been revised to improve reliability. The alpha coefficient for the Global subscale in the present study was 0.66. The scale is written for children at the third grade level.

According to Harter (1985), the SPPC is not appropriate for children below the third grade for several reasons. Younger children generally do not have the reading skills to follow the item content. Moreover, specific words, notably the trait labels are not yet understood by younger children since developmentally these generalizations do not emerge in the self-descriptions of children until middle childhood. Finally, younger children do not have a consolidated concept of their global self-worth as a person; therefore the score of this subscale is extremely unreliable when used with a younger population. The SPPC, because of the structure of the items, may not be appropriate for special populations of children such as those with learning disabilities and the author has constructed special versions of the scale for use with learning disabled children. Several siblings in the present study, including one 14 year-old female, had difficulty

understanding the format of the SPPC and required the assistance of the researcher in order to correctly complete the instrument.

The Resiliency Model of Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993) is based on the theory of symbolic interactionism, which rests upon the assumption that individuals actively set goals based on their individual perception. For this reason, the SPPC was felt to be suited for the study as the researcher was interested in the siblings' perception of their adaptation rather than the illness experience itself. The score on the Global subscale of the SPPC, which illustrates the child's perception of his or her overall competency, was entered into the hypothesized structural equation model as one indicator of the latent construct of adaptation.

Children's Depression Inventory (CDI). The CDI (Kovacs, 1985) is a 27-item self-rated symptom oriented scale suitable for school-aged children. Written at a 1st grade reading level, it requires the lowest reading level of any measure of depression for children (Berndt, Schwartz, & Kaiser, 1983). The instrument quantifies a range of depressive symptoms including disturbance in mood and hedonistic capacity, self-evaluation, vegetative functions, and interpersonal behaviors. The scale discriminates between children and adolescents with the psychiatric diagnosis of major depressive or dysthymic disorder as opposed to those with other psychiatric conditions or non-selected "normal" school children (Kovacs, 1992).

Based on empirical as well as theoretical evidence, the normative sample used for scoring the CDI was divided into groups based on age and gender. According to Kovacs (1992), the data indicated that dividing the sample into age and gender groups produced different CDI total scores. Developmental trends indicated the CDI total scores of

children aged 13 years and older were somewhat higher than those of children aged 12 years and younger. There are empirical as well as theoretical reasons for dividing the normative sample into two groups based on age. Data indicate that dividing the sample into these two groups produces different CDI total scores. The total CDI scores of children aged 13 years and older (mean = 10.5, SD = 7.3) are somewhat higher than those of children 12 years and younger (mean 8.9, SD = 7.3). Several items concern the consequences of depression in contexts that are especially relevant for children, for example; school (Kovacs, 1992). Each CDI item consists of three choices, keyed 0, 1, or 2, with higher scores indicating increasing severity (0 = absence of symptom, 1 = mild symptom and 2 = definite symptom). The CDI score is interpreted by analyzing the total CDI score and the scores on each of the five factors including negative mood, interpersonal problems, ineffectiveness, anhedonia and negative self-esteem. The total CDI score can range from 0 to 54, with higher scores indicating greater symptomatology. The instrument has concurrent and discriminant validity and a score of 13 may be interpreted as the criterion for identifying clinical depression in those instances where the CDI is not followed by a clinical evaluation (Smucker, Craighead, Craighead & Green, 1986). Cronbach's alpha for the 27-item instrument was found to equal 0.86, indicating good internal consistency reliability (Kovacs, 1992). The Cronbach's alpha coefficient for the present study was 0.80. Alpha coefficients for the five CDI factors are as follows: negative mood = 0.62, interpersonal problems = 0.59, ineffectiveness = 0.63, anhedonia = 0.66 and negative self-esteem = 0.68. The test-retest reliability for the CDI has been found to range from 0.47 to 0.62 for pediatric psychiatric patients (Nelson & Politano, 1990) and from 0.66 to 0.82 for pediatric non-psychiatric patients (Finch,

Saylor, Edwards & McIntosh, 1987). The instrument has both concurrent and discriminant validity. Sibling adaptation is the outcome of the child's response to living with type 1 diabetes (Lavee, McCubbin & Patterson, 1985). The total CDI score was included in the hypothesized structural equation model as one critical indicator of the latent construct of sibling appraisal.

Data Collection Procedures

The proposed study was approved by the Human Subjects Review Committee of the Yale University School of Nursing on July, 17, 2001 (Protocol #01-37). Assent was obtained from the sibling. After obtaining a written informed consent from the parent(s), and a written assent from the sibling, the investigator asked the sibling to complete four written instruments and the mother or father to complete a demographic data form and three written instruments.

Every effort was made to increase the convenience of the family and, therefore data were collected during a home visit. Every effort was made not to delay the interview once the participant and family had consented to the study. The potential lack of anonymity of each subject was addressed by not writing the subject's name or any other identifying information on the data collection forms. Each family group was assigned a code number. A codebook containing a master list of the subjects' questionnaire code numbers is kept by the investigator in a locked cabinet and shared with no one. Every parent and sibling was told that their decision regarding participation in the study would in no way effect the care of the child with diabetes and a subject might feel free not to respond to any specific question and/or to withdraw from the study at any point.

Data Analysis

Data Screening

The data from all parent and sibling instruments were double-entered into two Excel files to check for accuracy of input and missing data. Using computerized printouts the data from both files were verified and missing or erroneous input were corrected. Once the two data files were identical, the two files were replaced by a single corrected Excel file. Univariate descriptive statistics were inspected for out-of-range values and plausible means and standard deviations. The plausibility of the means and standard deviations of the indicator variables was assessed because the validity of any results rests on the quality of the data used. Missing data (three individual items) were substituted with the mean.

Scatterplots were used to check for skewness and kurtosis of each variable that was to be entered into the structural equation model. A variety of transformations were performed on the data, none of which improved the distribution of the data. Therefore, the original scores were used in the data analysis. Bivariate scatterplots of each pair of variables were done to check the assumption of linearity among the variables. No non-linear trend was observed with any pair of the variables. The assumption of homoscedasticity was met as the scatterplots illustrated an evenness of scatter rather than a fan-shaped design. Multicollinearity was not a problem among the variables as the squared multiple correlations ranged from .004 to .076.

Analysis Methods

The data were then entered into a structural equation model. Structural equation modeling is considered a causal modeling technique and can be performed with either

cross-sectional or longitudinal data. With structural equation modeling, it is imperative to use a conceptual framework to guide the data analysis. According to Norris (1997), theoretical assumptions of causation are made in the process of identifying a model to be tested as well regarding the measurement of latent variables and the relationships between latent variables. Questions 1 to 3 were analyzed using descriptive statistics and t-tests and Question 4 was analyzed using structural equation modeling.

CHAPTER 4: RESULTS

Introduction

The purpose of this descriptive study was to investigate the factors related to variation in adaptation for the siblings of children with type 1 diabetes. The research questions were:

1. What are the coping strategies used by siblings of children with type 1 diabetes as measured by the Schoolager's Coping Strategy Strategies Inventory (SCSI)?
2. What is the sibling's appraisal of living with type 1 diabetes in the family as measured by the knowledge, perception, and mood subscales of the Sibling Perception Questionnaire (SPQ)?
3. How well do the siblings of children with type 1 diabetes adapt to living with type 1 diabetes in the family as measured by the Children's Depression Inventory (CDI)?
4. Using structural equation modeling, what are the relationships among family typology as measured by the adaptability and cohesion subscales of the Family Adaptability and Cohesion Scale (FACES II) and the cohesion subscale of the Coping Health Inventory for parents (CHIP), social support and resistance resources as measured by the resource subscale of the Family Inventory of Resources for Management (FIRM) and the social support and communication subscales of (CHIP), sibling appraisal as measured by the perception and mood subscales of the Sibling Perception Questionnaire (SPQ) and the Children's Depression Inventory (CDI) and the sibling adaptation to

living with type 1 diabetes in the family as measured by the frequency and efficacy subscale of the Schoolager's Coping Strategy Strategies Inventory (SCSI), the knowledge subscale of the Sibling Perception Questionnaire (SPQ) and the global subscale of the Self- Perception Profile for Children (SPPC)?

Data were collected on a total of 128 siblings of children with type 1 diabetes from August 2001 to November 2001. Data were also collected from the parent in the family who was responsible for the majority of the care-taking activities. In all but three cases in which the parents were divorced and the father assumed the primary care-taking for the management of the diabetes, the mothers completed the instruments. To assure that there were no gender specific differences between males and females that would affect the results of the data on the parent questionnaires, t-tests were subsequently performed to compare the responses of the mothers to those of the fathers. There were no significant gender differences on any of the subscales of the instruments except for the cohesion subscale of FACES. Therefore, data collected from both the mother and the father were included in the final data analysis.

This chapter presents an analysis of the data for the research questions in this study. First, the descriptive data on all variables for this study are presented. Second, the first three research questions are answered using descriptive statistics and t-tests. Third, the fourth research question is analyzed using structural equation modeling.

Description of Sample

Demographics

Sibling Demographics

The mean age of the siblings was 11.2 years ($SD = 1.96$) with a range of 8-14 years. The grade range was Grade 2 - Grade 10 with a mode of Grade 6. The gender of the siblings was 53.1% female ($n = 68$) and 46.8% male ($n = 60$). The mean number of children in the family was 3.09 ($SD = 1.08$) with 23.4% of the siblings being the oldest, 42.9% being the second child, 22.6% being the third child, 7.0% being the fourth child and 3.9% being the fifth child. The largest segment of the sample, 103 cases (81.2%), did not report any significant health problems. In 24 cases (18.8%), the parent reported that the sibling had a minor health problem (allergies, atopic dermatitis, vision problems). Table 2 summarizes the sibling demographics.

Table 2

Descriptive Characteristics of Siblings

Variable	n	%
Age of sibling in years		
8	16	12.50
9	11	8.59
10	17	13.28
11	22	17.19
12	21	16.41
13	19	14.48
14	22	17.19
Grade of sibling		
2	2	1.56
3	14	10.94
4	9	7.03
5	23	17.97
6	20	15.63
7	20	15.63
8	17	13.28
9	21	16.41
10	2	1.56
Gender of Sibling		
Male	60	46.88
Female	68	53.13
Birth Order of Sibling		
First	30	23.44
Second	55	42.97
Third	29	22.66
Fourth	9	7.03
Fifth	5	3.91
Health of Sibling		
No health problems	104	81.25
Minor health problem	24	18.75

Demographics of the child with diabetes

The mean age of the child with diabetes was 12.2 years (SD = 4.42) with a range of 2 – 22 years. The mean duration of the type 1 diabetes was 60.1 months (SD = 44.53) or 5 years. Table 3 summarizes these data.

Table 3

Descriptive Characteristics of Children with Diabetes

Subjects (N = 128)		
Variable	n	%
Age of child in years		
2-5	6	4.68
6-11	46	35.93
12-18	67	52.36
19-24	9	7.03
Duration of Diabetes		
Less than 5 years	66	51.97
Five years or greater	62	48.03

Family demographics

Of the 128 families, 85.9% (n = 110) were White, 7.8% (n= 10) were Black and 6.3% (n= 8) were Hispanic. The largest segment of the sample was Catholic, 48.4% (n =62), followed by Protestant 26.5% (n = 34), Jewish 10.9% (n =14) and other 14.0 (n =18). Weekly services were attended by 46.0% (n = 59) of the families and monthly services were attended by 18.7% (n = 24) of the families. Twenty-five percent of the families (n = 33) rarely attended religious services and 8.5% (n = 11) of the families never attended religious services. The majority of the mothers were nonprofessionals, 57.0% (n = 73), while 42.1% (n = 73) were professionals. The majority of the fathers were professionals, 60.9% (n = 78), while 38.2% (n = 49) of the fathers were nonprofessional. The average years of education for the mothers was 14.9 years and 15.1 years of education for the fathers. Over half of the families had an annual income equal to or more than \$100,000.

Table 4

Descriptive Characteristics of the Family

Subjects (N = 128)		
Variable	n	%
Race		
White	110	85.94
Black	10	7.81
Hispanic	8	6.25
Religion		
Catholic	62	48.44
Protestant	34	26.56
Jewish	14	10.94
Other	4	14.06
Number of Children		
2	42	32.81
3		39.06
4	24	18.75
5	5	6.25
6	6	2.34
8	1	0.78
Father's Occupation		
Professional	79	61.72
Nonprofessional	48	37.50
Mother's Occupation		
Professional	54	42.19
Nonprofessional	73	57.03
Income		
Less than \$19,999	9	7.03
\$20,000-39,999	11	8.59
\$40,000-59,999	8	6.25
\$60,000-79,999	17	13.28
\$80,000-99,999	16	12.50
More than or equal to \$100,000	65	50.78

Research Question 1

The first research question examined the coping strategies used by the siblings of children with type 1 diabetes as measured by the SCSI. The Schoolager's Coping Strategies Inventory is designed to be a comprehensive measure of coping strategies used by school-aged children. The inventory is divided into 13 different domains of coping strategies. The mean frequency scores of the coping strategy domains in the two subscales (frequency, efficacy) are displayed in Table 5.

Table 5

Mean Scores on the SCSI for the Total Sample

Domain	Frequency Scale	Efficacy Scale
Relaxation	2.97	2.98
Distracting	2.95	2.91
Cognitive	2.62	2.65
Social support	2.58	1.64
Avoidant	2.19	2.14
Spiritual	2.02	2.65
Physical exercise	2.00	2.22
Emotional	1.96	2.13
Isolating	1.76	2.62
Habitual	1.60	2.34
Aggressive motor	0.91	1.03
Aggressive verbal	0.88	0.96
Other	2.57	2.90

Data explaining the descriptive statistics for the total scores on the frequency subscale and the efficacy subscale for the SCSI are displayed in Table 6. The two scales were positively and significantly correlated with each other ($r = 0.76$) at the alpha 0.01 level.

Table 6

Mean, Standard Deviations and Ranges for Subscales of the SCSI

Subjects (N= 128)	Mean	Standard Deviation	Range
Frequency Subscale	30.13	8.24	46
Efficacy Subscale	37.32	9.38	46

The following six domains of coping strategies identified those behaviors most commonly chosen by the siblings to deal with the stressors associated with living with type 1 diabetes in the family in the following order of frequency: relaxation, distraction, cognitive behaviors, social support, avoidance and spirituality.

Relaxation Domain

The coping behaviors making up the relaxation domain include “try to relax, stay calm” and “watch TV or listen to music.” Relaxation behaviors serve to detach oneself from contact with the stressor and therefore serve to relieve the stress. The domain had the highest mean score of all the domains in both the frequency scale as well as the efficacy scale suggesting that these were the most frequently used coping behaviors and the siblings found these behaviors very helpful in dealing with the stressors associated with living with type 1 diabetes.

Distraction Domain

Distraction was the second most common strategy chosen by the siblings to cope with living with type 1 diabetes. The behaviors in this domain include “to draw, write or read something” and to “play a game or something.” In many cases, especially for children, when the stressors cannot be changed (e.g. diabetes does not go away),

distracting behaviors are often chosen as coping strategies. As with the scores in the relaxation domain, the total average score of the efficacy scale in the distraction domain was also the second highest score suggesting a strong correlation between the siblings' choice of coping behaviors and their perception of the effectiveness of these behaviors.

Cognitive Behaviors Domain

The third most common coping strategy domain was the cognitive behavior domain. This domain included the behaviors to “think about it” and “to try and forget about it.” Cognitive behaviors serve to change the perception of the stressor or are an intellectual or emotional attempt to stop negative thoughts. As with the preceding two domains, the siblings rated these behaviors as effective in dealing with their stress.

Social Support Domain

Social support was the fourth most common coping strategy domain used by the siblings in this study. The two items in this domain were to “cuddle my pet or stuffed animal” or “talk to someone.” Reaching out to others serves to redirect feelings rather than centering the feelings within, and these behaviors are generally an effort to make oneself feel better about the situation. Though the siblings used the behaviors in this domain frequently, they did not rate these behaviors as being very effective as the average score on the frequency scale was considerably higher than the efficacy scale.

Avoidant Domain

The fifth most common domain chosen by the siblings to cope with living with type 1 diabetes was the avoidant domain. Similar to the items in the distraction domain, the items in this domain included “to daydream” or “to sleep or take a nap.” As with the distraction domain, the siblings did find the use of these behaviors to be effective.

Spirituality Domain

The sixth most common domain of coping behaviors was spiritual behaviors. The two behaviors included in this domain were “to pray” or “to say I’m sorry or to tell the truth.” As with cognitive behaviors, the behaviors in this domain serve to make oneself feel better about the experience and to better cope with the stressors associated with the experience. The siblings found these behaviors to be extremely effective in coping with stress, as the mean efficacy score was considerably higher than the mean frequency score.

The remaining coping strategy domains of isolating behaviors, habitual behaviors, emotional behaviors, physical exercise, aggressive motor behaviors, and aggressive verbal behaviors all had mean scores significantly lower than the mean scores on the preceding six domains of coping behaviors. However, with all of the domains the efficacy score for each individual domain was higher than the frequency score for that same domain. This may suggest that children may experiment with a variety of coping strategies that may work for them, but settle on a few that can best ameliorate their stress-coping experience.

Age and Gender Differences

The data were analyzed using t-tests to determine if there were differences based on age and gender. The t-tests for the sample based on age had a p value above .05, for both the frequency and efficacy subscale of the SCSi indicating that the sample was not significantly different based on age. The t-tests for sample means based on gender had a p value of .003 for the frequency subscale and a p value of .025 for the efficacy subscale indicating significant gender differences on both subscales. Based on the data of this study, females used more coping strategies and found them more effective. Tables 7-9

summarize the data for the descriptive statistics and t-tests for the frequency subscale and the efficacy subscales for the SCSI by age and gender.

Table 7

Mean, Standard Deviations and Ranges for Subscales of the SCSI by Age

	Mean	Standard Deviation	Range
<hr/>			
Age: 8-11 years			
Frequency Subscale	28.92	8.40	46
Efficacy Subscale	36.71	9.51	46
<hr/>			
Age: 12-14 years			
Frequency Subscale	31.41	7.93	39
Efficacy Subscale	37.98	9.28	43
<hr/>			

Table 7 shows that children in the 12-14 years group had slightly higher mean scores on both the frequency and efficacy subscales of the SCSI, but these differences were not significant. The findings of this study suggested that age does not appear to affect the use and frequency of coping strategies may be partially explained by the age grouping of the children. In particular, the cognitive processes associated with the use of coping strategies may not differ substantially children between the ages of 8-11 and 12-14 years. In other words, significant age differences may have been noted had the sample in this study included either younger school-aged children or older adolescents.

Table 8

Mean, Standard Deviations and Ranges for Subscales of the SCSI by Gender

	Mean	Standard Deviation	Range
<hr/> Male			
Frequency Subscale	27.88	7.91	32
Efficacy Subscale	35.35	9.64	44
<hr/> Female			
Frequency Subscale	32.11	8.06	42
Efficacy Subscale	39.07	8.86	42
<hr/>			

An examination of Table 8 shows that girls used more coping strategies than boys and found them more effective. The results of the t-tests displayed in Table 9 indicated that these gender differences are not statistically significant.

Table 9

Comparisons of SCSI based on Age and Gender

	t	df	Sig. (2-tailed)	Mean Difference
Age				
Frequency Subscale	1.72	126	.086	2.49
Efficacy Subscale	.765	126	.446	1.27
Gender				
Frequency Subscale	-2.99	126	.003	-4.23
Efficacy Subscale	-2.26	126	.025	-3.72

Table 10-12 summarize the differences between gender on the coping strategies most commonly used by the siblings of children with diabetes.

Table 10

Responses to the Frequency Subscale SCSI based on Gender

	t	df	Sig.	Mean (male)	Mean (female)
Domain/Item					
Relaxation					
Item: Try to relax	-3.21	126	.00	1.48	1.99
Watch TV	2.25	126	.82	2.08	2.12
Distracting					
Item: Draw/Write	-1.07	126	.04	1.48	1.99
Play a game	.913	126	.36	1.58	1.44
Cognitive					
Item: Think about it	-1.69	126	.09	1.50	1.78
Try to forget it	-1.49	126	.13	1.07	1.34
Avoidant					
Item: Daydream	.515	126	.60	1.42	1.32
Take a nap	-2.60	126	.79	1.40	1.46
Social Support					
Item: Cuddle my pet	-4.03	126	.00	.78	1.54
Talk to someone	-2.14	126	.03	1.13	1.50
Spiritual					
Item: Pray	-2.95	126	.00	.70	1.16
Say I'm sorry	-2.40	126	.01	1.58	2.00

As shown in Table 10, of the 12 coping strategy items included in the frequency scale of the SCSI, girls used 6 of the coping strategies (try to relax, draw/write, cuddle my pet, talk to someone, pray and say I am sorry) significantly more often. There were no coping strategy items in the frequency subscale that were used significantly more often by boys than girls.

Table 11

Responses to the Efficacy Subscale SCSI based on Gender

	t	df	Sig.	Mean (male)	Mean (female)
Domain/Item					
Relaxation					
Item: Try to relax	-3.21	126	.02	1.93	2.28
Watch TV	1.53	126	.12	2.28	2.25
Distracting					
Item: Draw/Write	-1.07	126	.29	2.03	2.26
Play a game	.913	126	.37	1.60	1.44
Cognitive					
Item: Think about it	-1.86	126	.06	1.80	2.12
Try to forget it	-1.53	126	.12	1.12	1.40
Avoidant					
Item: Daydream	.515	126	.60	1.42	1.32
Take a nap	-2.60	126	.79	1.40	1.46
Social Support					
Item: Cuddle my pet	-4.07	126	.00	.78	1.54
Talk	-1.30	126	.19	1.17	1.50
Spiritual					
Item: Pray	-2.95	126	.00	.70	1.16
Say I'm sorry	-2.40	126	.02	1.58	2.00

As shown in Table 11, of the 12 coping strategy items included in the efficacy subscale of the SCSI, girls found 4 of the coping strategies (try to relax, cuddle my pet, pray, say I'm sorry) to be significantly more effective than did boys. Likewise, there were no coping strategy items in the efficacy subscale that were found to be significantly more effective for boys than for girls.

Research Question 2

The second research question examined the sibling's appraisal of living with type 1 diabetes in the family as measured by the knowledge, perception, and mood subscales of the Sibling Perception Questionnaire (SPQ). The SPQ is comprised of the knowledge, perception and mood subscales. The results of this section were analyzed according to the subscales of the questionnaire. The items in the SPQ were scored as follows:

Never = 0, A little = 1, Sometimes = 2, A lot = 3 and Always = 4, with lower scores indicating a greater knowledge base of type 1 diabetes, a more positive perception of the illness, and a better overall mood. The possible range of scores was 0-20 for the knowledge subscale, 0-32 for the perception subscale and 0-32 for the mood subscale. The data for the SPQ are displayed in Table 12.

Table 12

Mean, Standard Deviations and Ranges for Subscales of the SPQ

Subjects (N= 128)	Mean	Standard Deviation	Range
Knowledge Subscale	6.50	3.33	15
Perception Subscale	8.25	4.27	21
Mood Subscale	10.89	4.85	19

The overall percentages for each of the individual subscales of the SPQ (knowledge, perception and mood) were computed by first adding the percentages of all of the items in each individual scoring category (Never = 0, A little = 1, Sometimes = 2, A lot = 3 and Always = 4). This score was then divided by the number of items in the subscale. For example, if in the knowledge subscale 12% of the siblings circled 0 for item 7, and

14% of the siblings circled 0 for item 8, and 18% of the siblings circled 0 for item 18, and 29% of the siblings circled 0 for item 19, and 57% of the siblings circled 0 for item 20; the sum of these percentage scores would be equal to 130. This score would be divided by 5 yielding an overall mean percentage of 26% of siblings who answered 0 on the knowledge subscale.

Knowledge Subscale

The knowledge subscale measured the extent of sibling's knowledge about type 1 diabetes. Data indicated that overall, 27.03% of the siblings answered never, 22.11% answered a little, 20.09% answered sometimes, 14.99% answered a lot and 15.78% answered always when asked questions regarding a if they felt a need to learn more about their brother's or sister's diabetes or if they were afraid of catching diabetes from their sibling. Questions geared toward assessing how knowledgeable the siblings were indicated that the majority of those questioned had some knowledge about the medical condition. The amount of knowledge, as well as the accuracy varied greatly. The mean score on the knowledge subscale indicated that the siblings did feel a need for more knowledge concerning the nature of type 1 diabetes.

Perception Subscale

The perception subscale measured the extent of sibling's perception or appraisal of type 1 diabetes. Results indicated that overall, 50.84% of the siblings answered never, 18.12% answered a little, 15.05% answered sometimes, 10.41% answered a lot and 5.58% answered always when asked questions describing a negative perception of their brother's or sister's diabetes. The mean score on the perception subscale indicated a positive appraisal of living with type 1 diabetes.

Mood Subscale

The mood subscale measured the extent of sibling's feelings about type 1 diabetes. The average percentages showed that overall, 60.70% of the siblings answered never, 18.16% answered a little, 9.72% answered sometimes, 3.97% answered a lot and 10.59% answered always when asked questions describing if they felt negative feelings regarding their brother's or sister's diabetes. The mean score on the perception subscale indicated a positive mood state related to the experience of living with type 1 diabetes.

The responses on the Sibling Perception Questionnaire raised some important issues. Almost three quarters of the children did not understand why their parents had to spend more time with the brother or sister with diabetes. Even though the data suggested that the majority of the siblings did not understand the time demands of the illness, the majority of the siblings did not feel ignored by their parents or other friends/family, did not feel that their family time was decreased, or felt that they had extra chores to do around the house.

More than half of the siblings felt that they could bother their parents with their worries and that they could talk to their parents about their brother's/sister's diabetes. Almost all of the children responded that others cared about their feelings. Furthermore, nearly three quarters of the siblings felt that they could have a good time even though their brother/sister was sick.

Two dominant areas of the illness experience that appeared to affect the siblings' adaptation related to the child's mood. Several siblings responded that they felt sad or mad about their brother's or sister's diabetes and most siblings expressed that they wished that they could do something to make their brother or sister feel better.

Additionally, more than half of the children reported a lack of resources for coping with their mood.

Age and Gender Differences

The data were analyzed using both descriptive statistics and t-tests to determine if there were differences based on age and gender. The t-tests for the sample based on age all had a p value above .05, indicating that the null hypothesis that the two groups are not significantly different on the knowledge, perception and mood subscale with respect to age is true. The t-tests for the sample based on gender also had a p value above .05, indicating that there are no significant mean gender differences. Tables 12- 14 summarize the data for the descriptive statistics and t-tests for the frequency subscale and the efficacy subscales for the SPQ by age and gender.

Table 13

Mean, Standard Deviations and Ranges for Subscales of the SPQ by Age

Subjects (N= 128)	Mean	Standard Deviation	Range
8-11 years			
Knowledge Subscale	6.72	3.50	15
Perception Subscale	8.43	4.85	18
Mood Subscale	11.37	4.62	17
12-14 years			
Knowledge Subscale	6.25	3.15	15
Perception Subscale	8.04	3.56	16
Mood Subscale	10.38	5.07	19

Results indicated that the mean scores for the knowledge, mood and perception subscales of the SPQ between age groups were very comparable. The mean difference for both the knowledge and mood subscale was less than 0.5. The greatest difference between age groups was noted for the mood subscale and this difference, however, was still <1.0 .

Table 14
Mean, Standard Deviations and Ranges for Subscales of the SPQ by Gender

Subjects (N= 128)	Mean	Standard Deviation	Range
Male			
Knowledge Subscale	6.26	3.49	15
Perception Subscale	8.30	4.85	20
Mood Subscale	10.56	45.24	19
Female			
Knowledge Subscale	6.70	3.19	13
Perception Subscale	8.20	4.09	20
Mood Subscale	11.19	4.49	19

The data comparing the mean scores for the knowledge, mood and perception subscales of the SPQ between genders were almost identical to the scores comparing age groups. Once again the mean difference for both the knowledge and mood subscale was <0.5 and the difference between gender for the mood subscale remained <1.0 .

Table 15

Comparisons of SPQ based on Age and Gender

	t	df	Sig. (2-tailed)	Mean Difference
<hr/> Age				
Knowledge Subscale	.798	126	.427	-.469
Perception Subscale	-1.15	123	.251	-.991
Mood Subscale	.521	119	.603	.391
Gender				
Knowledge Subscale	-.739	120	.462	-.439
Perception Subscale	-.718	117	.474	-.624
Mood Subscale	-.123	120	.902	.941

As shown by the results of the t-tests in Table 15, there were no significant differences on any of the subscales based on either age or gender. In summary, the data from the SPQ indicated that the siblings' level of medical information about type 1 diabetes was adequate but that the siblings felt a need to know more about the illness. The findings from the perception subscale revealed that the siblings rated their perception of living with the illness as more positive than negative. The data from the mood subscale suggested an overall positive mood state in relation to the experience of living with type 1 diabetes.

Research Question 3

The third research question examined the adaptation of siblings of children with type I diabetes as measured by the Children's Depression Inventory (CDI). The CDI cut-point for depression can be set at different places depending upon whether the researcher is more interested in minimizing false negatives or false positives. Usually, in a clinical setting the researcher wants to minimize the false negatives so one would want to set the cut-point relatively low (12 or 13), because an identified child would then receive detailed clinical assessment and diagnosis. However, in general purpose screening, the researcher usually wants to minimize the probability of false positives because it is not desirable to label a child with a pathological label unless it is actually warranted. Since the data collection procedure for the present study was done in the home environment, the cut-point for depression was set at 16 and above.

The CDI scores for the sample ranged from 0 to 30 (mean = 5.7, SD = 5.2). According to Kovacs (1992), the mean CDI score for Toronto public children (N = 860) was 9.2 with a standard deviation of 7.30. The mean CDI score for the sample (5.7) indicated this group was below average in depression as compared with the general population for children aged 8 – 14 years, only 1.6% scored 20 or greater. The data for the CDI are displayed in Table 16.

Table 16

Mean, Standard Deviation and Range for the CDI

Subjects (N= 128)	Mean	Standard Deviation	Range
Children's Depression Inventory	5.68	5.21	30

Six siblings had a score of 16 or above and none of the children in the sample chose the response, "I want to kill myself" when asked if they ever thought about killing themselves. There were 28 male siblings in the study aged 8-11 years. Within this group, the scores ranged from 0 to 30 (mean = 6.5, SD = 6.6). One 8 year-old, one 9 year-old, one 10 year-old had a total CDI score of 16 or above. There were 38 females in the study aged 8-12 years. Within this group, the scores ranged from 0 to 14 (mean = 4.9, SD = 4.3) with none of the subjects scoring 16 or above.

There were 32 male siblings in the study aged 12-14 years. Within this group, the scores ranged from 0 to 20 (mean = 6.0, SD = 4.3). One 12 year-old male and one 14 year-old male had a total CDI score of 20. There were 30 female siblings in the study aged 12-14 years. Within this group, the scores ranged from 0 to 17 (mean = 5.3, SD = 4.6). One female aged 14 years had a total CDI score of 17. According to the results of the present study, it appears that male school-aged children and young adolescents scored higher than females on the CDI. The data summarizing the scores on the CDI are included in Table 17.

Table 17

Frequency of Scores on the CDI

Subjects (N= 128)	Males (%)	Females (%)
CDI score <16		
Age 8-11	19.50	29.64
Age 12-14	23.4	22.62
CDI >16		
Age 8-11	2.34	0
Age 12-14	1.56	.78

Research Question 4

The fourth research question examined the relationships among family typology as measured by the Family Adaptability and Cohesion Scale (FACES II) and the cohesion subscale of the Coping Health Inventory for Parents (CHIP), social support and resistance resources as measured by the resource subscale of Family Inventory of Resources for Management (FIRM) and the social support and communication subscales of the Coping Health Inventory for Parents (CHIP), sibling appraisal as measured by the perception and mood subscales of the Sibling Perception Questionnaire (SPQ) and the Children's Depression Inventory (CDI) and sibling adaptation to living with type 1 diabetes in the family as measured by the Schoolager's Coping Strategy Strategies Inventory (SCSI), the knowledge subscale of the Sibling Perception Questionnaire (SPQ) and the global subscale of the Self-Perception Profile for Children (SPPC). The purpose of this analysis is to specify, estimate and examine the causal relationships among social support, family typology, sibling appraisal and sibling adaptation using structural equation modeling.

Structural equation modeling is a statistical procedure designed to assess the ways in which a set of constructs relate to one another in a multivariate framework (Wagner, Scholl & Gipson, 1998; Tabachnick & Fidell, 1997). The causal model to be tested consists of the structural equation model (SEM) and the measurement model (MM) (Joreskog & Sorbom, 1989). The SEM consists of latent variables, unobserved constructs, which are depicted by circles. The latent variables are not measured directly but rather are measured through the critical indicators that they are intended to operationalize (Maruyama, 1998). These indicators, which are observed or manifest variables, are indicated by squares (Anderson & Gerbing, 1984).

Latent variables in the model may be exogenous (independent), or endogenous (dependent) variables. Exogenous variables are causal variables by but not caused by the relationships in the model. Alternately, endogenous variables are caused by other variables in the model and may themselves be causes. Parameters are denoted by arrows and refer to the pathways in the causal model and can be paths between two exogenous variables, two endogenous variables or an endogenous variable and an exogenous variable. Hypotheses are noted by arrows, and a single directed arrow denotes causation while a double-headed arrow denotes correlation. A curved arrow represents a noncausal relationship. The disturbances, termed residuals in regression analyses, represent all causes of the variable not accounted for by the structural equation model (Hoyle, 1995). According to Maruyama (1998), structural equation modeling allows for a more precise test of theory as it enables the researcher to assess direct and indirect effects of the variables in the model simultaneously. Figure 2 illustrates the hypothesized structural equation model in this study and Figure 3 illustrates the hypothesized measurement model.

Structural Equation Model

The structural equation models tested were covariance structure models with multiple critical indicators for the latent variables. The present analysis followed a two-step procedure (measurement model and structural model). Both the measurement model and structural model were tested and revised until a statistically acceptable model was found, based on goodness-of-fit indices. Table 18 summarizes the latent variables and the critical indicators used for the hypothesized structural equation model in this study.

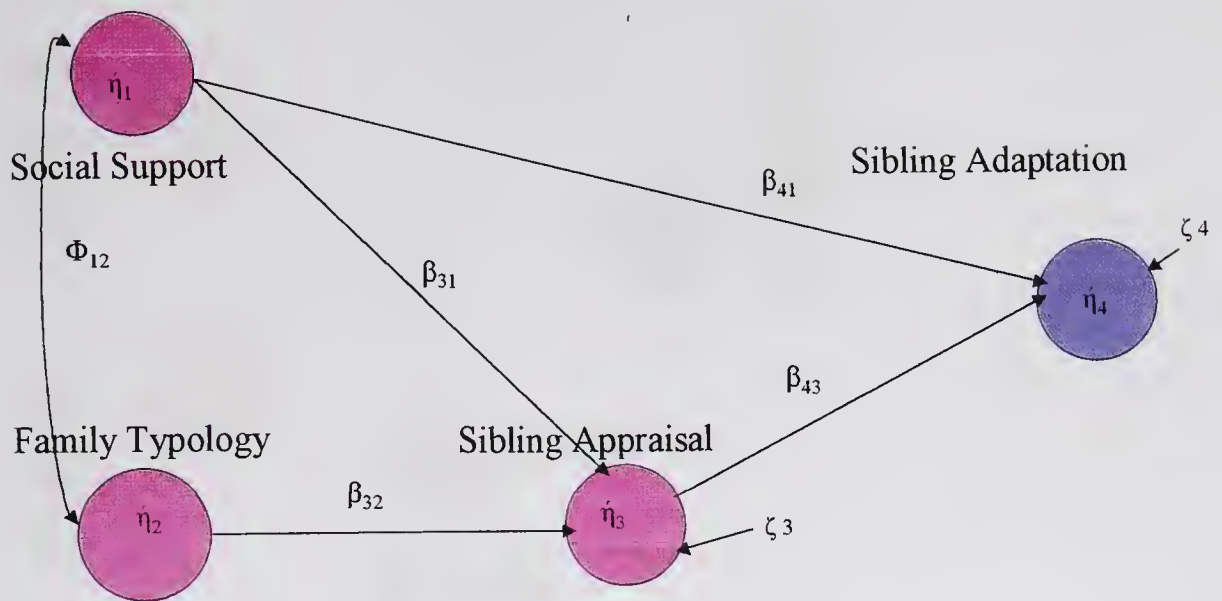
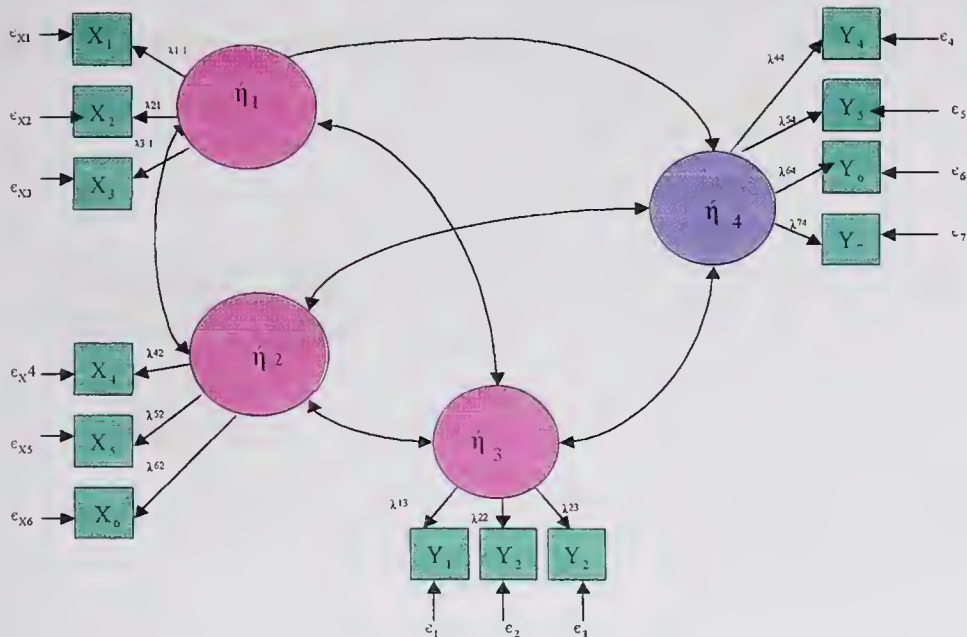


Figure 2: *Hypothesized Structural Equation Model*



Latent Variables	Indicators	Social Support η_1	x1
=social support	x2=resources x3= communication		
Family Typology η_2	x4 =cohesion x5=cohesion x6= adaptability		
Sibling Appraisal η_3	y1=perceptions y2= mood y3 =depression		
Sibling Adaptation η_4	y4 =frequency coping strategies y5 = efficacy coping strategies y6= knowledge y7= global perception		

Figure 3: *Hypothesized Measurement Model*

The causal model, which combines the structural equations model and the measurement model, provides estimates of the strengths of all the hypothesized relationships between variables in a theoretical model (Maruyama, 1998). Figure 4 illustrates the hypothesized causal model.

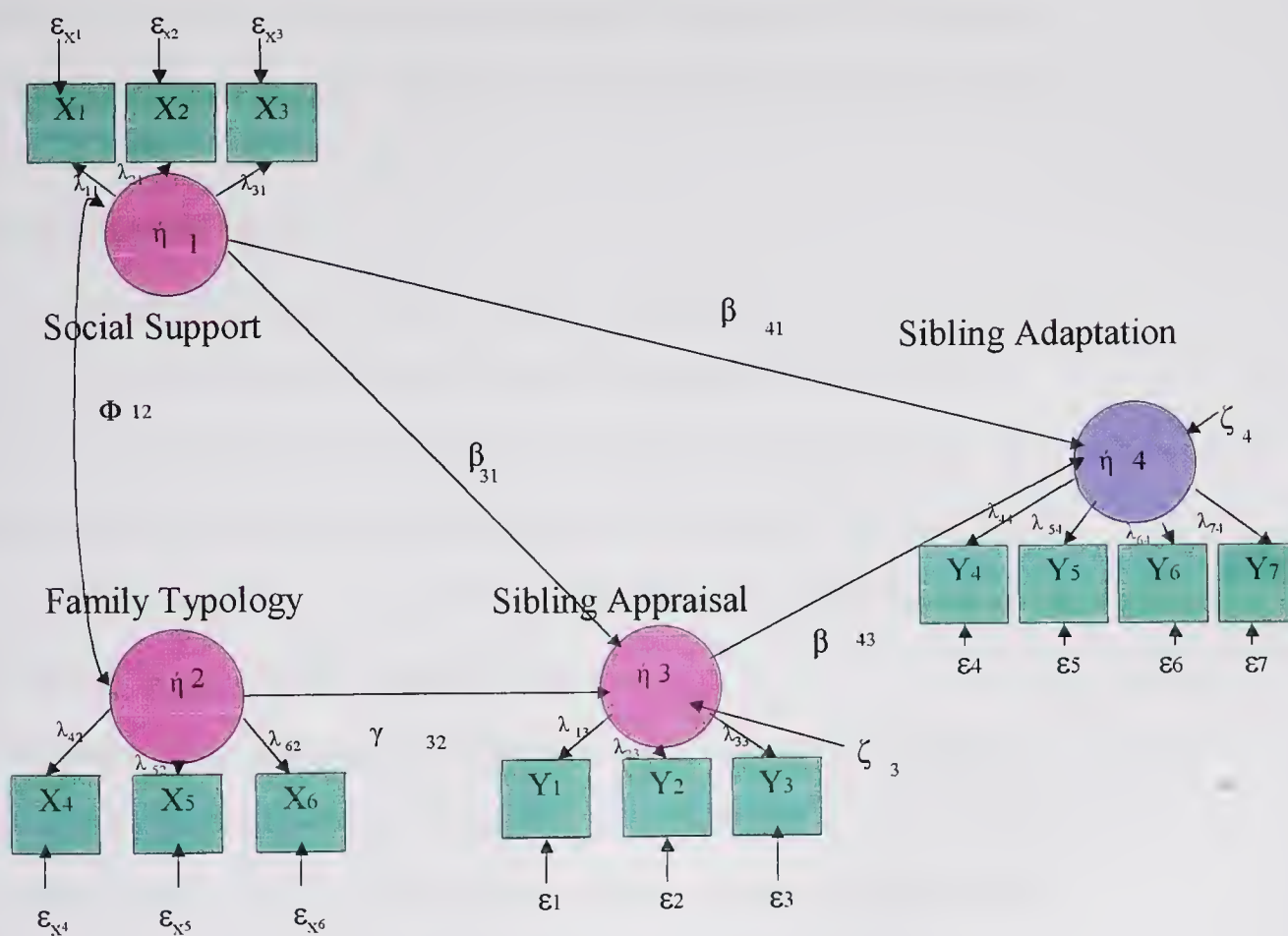


Figure 4: *Hypothesized Causal Model*

According to Bollen (1983) the first step, model specification, refers to the initial model that a researcher formulates prior to estimation. The causal model being tested should first be specified in a path diagram that presents the hypothesized causal linkages among variables (Polit, 1996). A path diagram illustrates the expected relationships between the endogenous variables (those affected by other variables in the model) and the exogenous variables (variables whose determinants are presumed to lie outside the model). This model is formulated on the basis of one's own theory or previous research in the area.

Structural Equation Model

In this study the structural equation model is composed of two exogenous variables, social support (η_1) and family typology (η_2); and two endogenous variables, sibling appraisal (η_3) and sibling adaptation (η_4). The causal paths are designated by betas (β), with the subscripts designating the effect and cause. The noncausal path is designated by phi (ϕ). The residual paths, which represent all other causes of the latent variable not accounted for by the model are designated by zeta (ζ).

In this model, social support is hypothesized to have a direct effect on sibling appraisal and sibling adaptation. Family typology is hypothesized to have a direct effect on sibling appraisal. Social support is hypothesized to have an indirect effect on sibling adaptation through sibling appraisal. Family typology is hypothesized to have an indirect effect on sibling adaptation through sibling appraisal. There is a noncausal relationship between social support and family typology indicated by a curved arrow.

Figure 3 illustrates the measurement model. Family typology was measured by three indicators including the cohesion scale of the CHIP, the adaptability subscale of FACES II and the cohesion subscale of FACES II. Social support was measured by three indicators including the resource subscale of FIRM, the community support scale of the CHIP and the communication subscale of the CHIP. The latent construct of sibling appraisal was measured by three indicators including the perception and mood subscales of the SPQ and the total score on the CDI. The latent construct of sibling adaptation was measured by four indicators including the global subscale of the SPPS, the knowledge subscale of the SPQ and the frequency and efficacy subscales of the SCSI.

The indicators for the exogenous variables are designated by χ with subscripts and the indicators for the endogenous variables are designated by y with subscripts (Hayduk, 1987, Emmons, 1992). The first subscript gives the number of the indicator, the second subscript refers to the latent variable. The path from each indicator to its latent variable is designated by lambda (λ) with subscripts. The measurement error associated with each indicator is designated by epsilon (ϵ). The notation used in this study was based on the four-matrix LISREL solution (Hayduk, 1987). Table 18 lists the latent variables and the critical indicators defining these latent variables.

Table 18

*Latent Variables with Critical Indicators for Hypothesized Measurement Model***Social Support**

Support subscale of CHIP
 Communication subscale of CHIP
 Resource subscale of FIRM

Family Typology

Cohesion subscale of FACES
 Adaptability subscale of FACES
 Cohesion subscale of CHIP

Sibling Appraisal

Mood subscale of SPQ
 Perception subscale of SPQ
 Children's Depression Inventory

Sibling Adaptation

Efficacy subscale of SCSI
 Frequency subscale of SCSI
 Knowledge subscale of SPQ
 Global subscale of SPPC

*Model Identification**Identification of Hypothesized Structural Model*

Identification determines whether it is possible to find unique values for the parameters of the model. Once the model is identified, it is estimated through structural equation modeling. Identification of the structural equation model requires that there be at least as many known as unknown parameters (Emmons, 1992; Bollen, 1983). The number of known variables is determined by the formula $k(k-1)/2$ where k is equal to the number of latent variables (Emmons, 1992; Bollen, 1983). The number of unknowns is

the sum of the number of pathways between latent variables, the number of correlations between exogenous variables and the number of correlations between disturbances (Emmons, 1992; Kenny, 1979). If there are as many knowns as unknowns, the model is said to be just-identified. If there are more knowns than unknowns, the model is said to be over-identified. If there are more unknown parameters than known parameters, the model is said to be under-identified. A model must be just-identified or over-identified in order to establish identification.

Using this definition, the hypothesized structural model in this study has met the conditions necessary for identification. There are four latent variables (social support, family typology, sibling appraisal, sibling adaptation). Therefore, the number of known in this study is $4(4-1)/2 = 6$. The present model is over-identified as there are 6 known parameters and 5 unknown parameters, 4 paths among latent variables and 1 correlation between the exogenous variables. There were no correlations among disturbances. Both just-identified and over-identified variables can be tested with LISREL (Polit, 1996). The hypothesized causal model in the present study is identified as the measurement model is identified.

Identification of Measurement Model

In order for a model to be estimable, it must be identified. In order for latent variables to be identified, both the measurement model and the structural model need to be identified (Rigdon, 1995). According to Maruyama (1998), there are two conditions that must be met to ensure identification. Identification of the measurement model requires that each latent construct has at least two critical indicators, however a construct

may have only one critical indicator if that loading is set to one. Secondly, each endogenous variable in a reciprocal relationship needs its own separate indicators.

The hypothesized measurement model in the present study is identified as each latent variable by two or more indicators. Social support and appraisal each have three indicators and family typology and adaptation each have two indicators. For the constructs that had two variables, both of the indicators were correlated with the indicator of another latent variable and the errors of both the indicators were uncorrelated with the error of the other indicator. There are no reciprocal relationships among the variables.

Estimation of the Measurement Model

The measurement model must be estimated and examined for data fit before the structural model is evaluated. To ensure identification, certain conditions must be met (Maruyama, 1998). The purpose of estimation is to determine if the indicators in fact define the latent variables that they are denoted to measure, and to adjust the measurement model to obtain model fit if they do not. This step is critical because if the indicators of a construct are not correlated with that construct, any statements regarding the causes and effects of that construct are invalid (Bollen, 1993).

Estimation of the measurement model was done through confirmatory factor analysis (CFA) using the LISREL 8 (Jöreskog & Sörbom, 1994). Confirmatory factor analysis differs from exploratory factor analysis in that the indicators that load on each factor are specified a priori. According to Jöreskog and Sörbom (1994), complex forms of confirmatory factor analysis not only guide the researcher as to the appropriate number of factors, but also allow the researcher to specify what variables relate to which factors and to identify relationships between variables that are not captured by these factors.

Therefore, the goal of confirmatory factor analysis is to identify latent variables that underlie the set of variables that are measured.

According to Bollen (1993), confirmatory factor analysis evaluates specification through appraisal of the paths (λ) between the indicators and the latent variables, and of their error variance (ϵ). The t -value is the statistic for evaluating factor loading and error variance. A significant t -value for a loading means that the indicator has a correlation to the latent variable that is greater than would be expected due to chance alone (Bollen, 1993). In an ideal measurement model, an indicator should load significantly on the latent variable that it is specified to measure, and on no other latent variable. If the error variance of an indicator is not significant, this implies that the indicator fully defines the latent variable and that no other critical indicator of that latent variable is required. In this case, the critical indicator alone can be used in place of the latent variable. The Z -values ≥ 1.96 or ≤ -1.96 are significant.

Hypothesized Measurement Model

This hypothesized measurement model (see Figure 4) was estimated using the maximum likelihood method. Five values, the p value for the model Chi-Square test, Chi-Square/df ratio, the comparative fit index (CFI), the non-normed-fit index (NNFI) and the root mean squares error of approximation (RMSEA) were used as goodness of fit indices (Bollen, 1993). Table 19 summarizes the goodness of fit statistics for the hypothesized measurement model. For the covariance matrix used in the data analysis refer to Appendix I.

Table 19

Goodness of Fit Statistics for Hypothesized Measurement Model

Degrees of Freedom = 59
 Minimum Fit Function Chi-Square = 215.94 ($p = 0.00$)
 Non-Normed Fit Index (NNFI) = 0.54
 Comparative Fit Index (CFI) = 0.66
 Root Mean Squares Error of Approximation = 0.16

Testing the Measurement Model

The goodness of fit indices compare the hypothesized model to the fit of another model. In the case where there is no other model specified, LISREL defaults to comparing the hypothesized model with the independence model (Jöreskog. & Sörbom, 1996). The independence model is the null model, which is the model in which the latent variables are assumed to uncorrelated. Additionally, the t values of the parameter significance test for path coefficients are reviewed to determine whether or not the path coefficient is significant. Lastly, based on the modification indices, the hypothesized relationships between latent variables and, also, between latent and non-indicator manifest variables are modified to obtain a structural model of acceptable fit. The goodness of fit indices include the following:

Normed Fit Index. The normed fit index (NFI), also known as the Bentler-Bonnett normed fit index, varies from 0 to 1 (Bentler, 1990). The normed fit index reflects the proportion by which the researcher's model improves fit compared to the null model. The value of the normed fit index should exceed .80 in order to indicate that the measurement model provides good fit for the data.

Non-Normed Fit Index. The non-normed fit index (NNFI), also known as the Bentler-Bonnett non-normed fit index, is similar to the normed fit index, however this goodness of fit index is not guaranteed to vary from 0 to 1 and is less affected by sample size (Maruyama, 1998). A NNFI value below .90 indicates a need to re-specify the model.

Comparative Fit Index. The comparative fit index (CFI) compares the existing model fit with a null model which assumes the latent variables in the model are uncorrelated. The CFI varies from 0 to 1. The CFI should be equal to or greater than .90 to accept the model, denoting that 90% of the covariation in the data can be reproduced by the given model.

Root Mean Square Error of Approximation: The root mean square error of approximation, also known as RMSEA or RMS measures the discrepancy per degree of freedom. The root mean square error of approximation should be below 0.10 in order to signify that the measurement model provides good fit for the data (Bentler, 1990).

The hypothesized model in the present study did not meet the conditions for good model fit, therefore running a structural model from the hypothesized measurement model was not attempted. In order to run a structural model, the Chi-Square must be significant ($> .05$). As stated previously, a non-significant p value (above 0.05 and preferably closer to 1.00), indicates that the hypothesized model and the true model for the population are not significantly different. In the hypothesized measurement model, the p value for the model Chi-square test (< 0.01), was statistically significant suggesting a poor model fit that needs respecification and reestimation. Additionally, the normed fit index (NFI) was < 0.80 indicating poor model fit and both the comparative fit index

(CFI) and the non-normed fit index were < 0.90 indicating poor model fit and the need for respecification and reestimation. The RMSEA value of 0.16 in the hypothesized model also exceeded the acceptable value of $< .10$, further indicating a lack of close fit. Additionally, an examination of the correlation matrix suggested that the CDI did not correlate with any of the other variables (the p values ranged from $.2 - .92$). Therefore, the CDI was removed from the final model.

There was a significant relationship ($p = .00$) between the frequency subscale of the SCSi and the efficacy subscale of the SCSi, suggesting that these two indicators were a good measure of sibling adaptation. Likewise, there was a significant relationship ($p = .00$) between the perception subscale of the SPQ and the mood subscale of the SPQ, suggesting that these two indicators were a good measure of sibling appraisal. Two of the three critical indicators that measured family typology (cohesion and adaptability) were also significant at the $.01$ level indicating that they appeared to be a good measure of family typology. Therefore, these critical indicators remained the same in the revised model. The factor loading for the global scale of the SPPC was the only non-significant value seeming to suggest that the SPPC did not fit well with the data.

The squared multiple correlation for the critical indicators is an indication of the quality of those variables as measures of their latent variables with higher values suggesting that the critical indicator is a good measure of the latent variable (Jöreskog, & Sörbom, 1996). The squared multiple correlations for several of the indicators ranged from acceptable to good. The indicators with acceptable values were as follows: resource subscale of FIRM (0.26), cohesion subscale of FACES II (0.71), adaptability subscale of FACES II (0.74), perception subscale of SPQ (0.86), mood subscale of SPQ

(0.31), frequency subscale of SCSi (0.86), and efficacy subscale of SCSi (0.66). The variables with low squared multiple correlations were as follows: cohesion subscale of CHIP (0.08), social subscale of CHIP (0.08), communication subscale of CHIP (0.07), CDI (0.14), the knowledge subscale of SPQ (0.07) and the global subscale of the SPPC (0.00). The indicators with acceptable values were included in the revised model and those with low values that were important to the theoretical framework were also included in the revised model. The value of zero for the global subscale of the SPPC suggested that this critical indicator was not a measure of sibling adaptation and therefore was removed from the model. The cohesion subscale had a low squared multiple correlation and did not correlate well with the other indicators of family typology and was not included in the revised model.

The Revised Measurement Model

Respecification

The revised measurement model was respecified in effort to improve model fit. The respecified model was as follows: Family typology was measured by two indicators, the adaptability subscale of FACES II and the cohesion subscale of FACES II. Social support was measured by three indicators including the resource subscale of FIRM, the community support scale of the CHIP and the communication subscale of the CHIP. The latent construct of sibling appraisal was measured by three indicators, the perception, knowledge and mood subscales of the SPQ. The latent construct of sibling adaptation was measured by two indicators, the frequency and efficacy subscales of the SCSi.

Testing of the Revised Measurement Model

The revised measurement model was much improved over the hypothesized model, however there was still poor model fit. Analysis of the revised model, as summarized in Table 20, indicated that the revised model did not fit the data sufficiently well. The chi-square measure of goodness of fit, with 29 degrees of freedom, was 59.52 ($p < .001$) and the non-normed fit index was < 0.90 indicating a discrepancy between the data and the relations specified in the model. However, the normed fit index (NFI) was $> .80$ and the comparative fit index (CFI) was > 0.90 indicating acceptable model fit. The RMSEA value of 0.088 was less than the acceptable value of $< .10$, also indicating acceptable fit.

The only significant modification indices were in the theta-epsilon matrix (covariance among error terms of measured variables), namely between the cohesion subscale of FACES II and the resource subscale of FIRM. These results suggested that the model could be improved by allowing the error variance of the cohesion subscale of FACES II to covary with the error variance of the resource subscale of FIRM. In other words, the results indicated that some of the residuals of these measures might have been nonrandom. Allowing these residuals to covary would have the effect of refining the model, since estimates of the structural effect of the corresponding latent variables would be controlled for.

Table 20

Goodness of Fit Statistics for Revised Measurement Model

Degrees of Freedom = 29
Minimum Fit function Chi-Square = 59.52 (P = 0.00)
Normed Fit Index = 0.86
Non-normed Fit Index (NFI) = 0.87
Comparative Fit Index (CFI)= 0.92
Root Mean Square Error of Approximation = 0.088

The Final Measurement Model

The final measurement model is illustrated in Figure 5. The final model resulted from the reestimation and respecification of the earlier models based on examination of the modification indices and theoretical considerations. The high value of the theta epsilon modification indices between the cohesion indicator (latent variable of family typology) and the resource indicator (latent variable of social support) suggested a need to correlate the error terms between these two variables.

Theoretical considerations implied that the three critical indicators, sibling perception, sibling knowledge and sibling mood, are related to the sibling's appraisal of living with a chronic illness. The frequency and efficacy of coping strategies may be significantly related to adaptive behaviors and a predictor of adaptation (Gamble, 1991) and as such defined the latent variable of adaptation. For these reasons, in the final model, the latent variable of sibling appraisal was defined by the sibling perception, sibling knowledge and sibling mood subscales of the SPQ, and the latent variable of sibling adaptation was defined by the frequency and efficacy subscales of the SCS1.

Table 21 summarizes the latent variables and the critical indicators used for the final structural equation model in this study.

Table 21

Latent Variables with Critical Indicators for Final Structural Equation Model

Social Support

Support subscale of CHIP

Communication subscale of CHIP

Resource subscale of FIRM

Family Typology

Cohesion subscale of FACES

Adaptability subscale of FACES

Sibling Appraisal

Mood subscale of SPQ

Perception subscale of SPQ

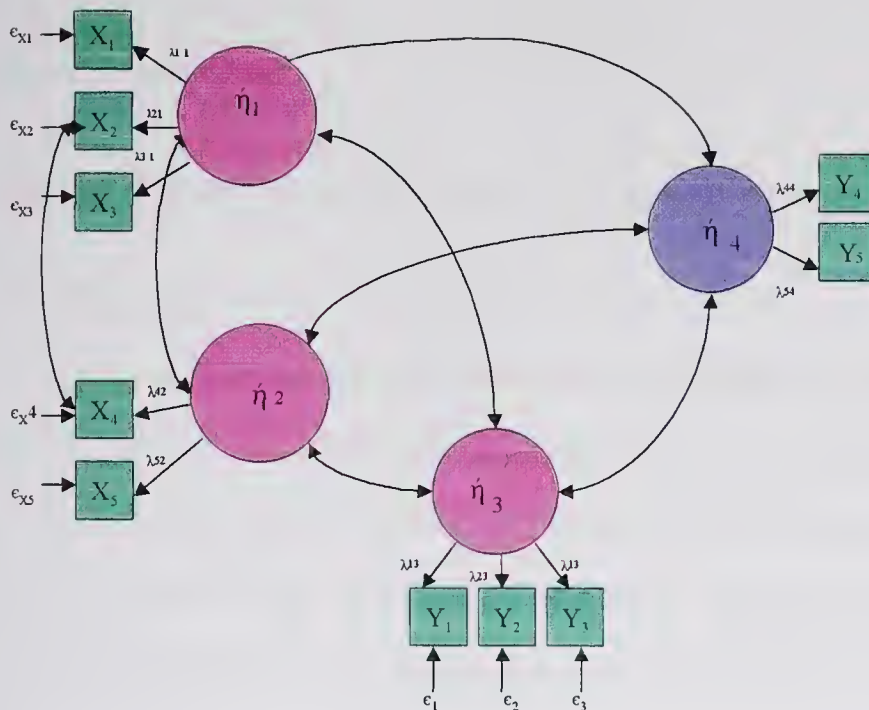
Knowledge subscale of SPQ

Sibling Adaptation

Efficacy subscale of SCSi

Frequency subscale of SCSi

The final model was much improved over the previous models and resulted in fair model fit. The goodness of fit statistics for the final measurement model are summarized in Table 22.



Latent Variable	Indicators
Social Support η_1	x_1 =social support x_2 =resources x_3 = communication
Family Typology η_2	x_4 =cohesion x_5 = adaptability
Sibling Appraisal η_3	y_1 =perceptions y_2 = mood y_3 = knowledge
Sibling Adaptation η_4	y_4 =frequency coping strategies y_5 = efficacy coping strategies

Figure 5. Final Measurement Model

Table 22

Goodness of Fit Statistics for Final Measurement Model

Degrees of Freedom = 28

Minimum Fit Function Chi-Square = 36.50 (P = 0.13)

Normed Fit Index = 0.91

Non-normed Fit Index (NFI) = 0.96

Comparative Fit Index (CFI) = 0.98

Root Mean Square Error of Approximation (RMSEA) = 0.049

Model Identification of Final Measurement Model

In order for a model to be estimable, it must be identified. In order for latent variables to be identified, both the measurement model and the structural model need to be identified (Rigdon, 1995). According to Maruyama (1998), there are two conditions that must be met to ensure identification. Identification of the measurement model requires that each latent construct has at least two critical indicators, however a construct may have only one critical indicator if that loading is set to one. Secondly, each endogenous variable in a reciprocal relationship needs its own separate indicators.

The final measurement model in the present study is identified as each latent variable by two or more indicators. Social support and appraisal each have three indicators and family typology and adaptation each have two indicators. For the constructs that had two variables, both of the indicators were correlated with the indicator of another latent variable and the errors of both the indicators were uncorrelated with the error of the other indicator.

Identification of the structural equation model requires that there be at least as many known as unknown parameters (Bollen, 1983). The number of known variables is determined by the formula $k(k-1)/2$ where k is equal to the number of latent variables (Bollen, 1983). The number of unknowns is the sum of the number of pathways between latent variables, the number of correlations between exogenous variables and the number of correlations between disturbances (Kenny, 1979). If there are as many knowns as unknowns, the model is said to be just-identified. If there are more knowns than unknowns, the model is said to be over-identified. If there are more unknown parameters than known parameters, the model is said to be under-identified. A model must be just-identified or over-identified in order to establish identification.

Using this definition, the final structural equation model in this study has met the conditions necessary for identification. There are four latent variables (social support, family typology, sibling appraisal, sibling adaptation). Therefore, the number of known in this study is $4(4-1)/2 = 6$. The present model is over-identified as there are 6 known parameters and 5 unknown parameters, 4 paths among latent variables and 1 correlation between the exogenous variables. There were no correlations among disturbances. Both just-identified and over-identified variables can be tested with LISREL (Polit, 1996). The final causal model in the present study is identified as both the measurement model and the structural model are identified.

Estimation and Testing of Final Structural Model

The goodness of fit statistics for the final structural model are summarized in Table

Table 23

Goodness of Fit Statistics for Final Structural Model

Degrees of Freedom = 29
Minimum Fit function Chi-Square = 36.85 (P = 0.15)
Normed Fit Index = 0.91
Non-normed Fit Index (NFI) = 0.97
Comparative Fit Index (CFI)= 0.98
Root Mean Square Error of Approximation = 0.047

The error terms, or residual terms, represent the factors not included in the model that affect the endogenous variables. The error terms of the final structural model are summarized in Table 24. All variables, except for the mood scale of the SPQ, the frequency and efficacy subscales of the SCSL, and the adaptation subscale of FACES had significant error. Significant error indicates that the critical indicators are different enough from one another to adequately define the latent variable (Mayutama, 1998).

Table 24

Error terms of Indicator Variables in Final Measurement Model

Latent Variable	Theta	Standard Error	Standardized Solution
Social Support			
Support subscale of CHIP	50.76	7.98	0.78
- Communication subscale of CHIP	6.76	1.34	0.67
- Resource subscale of FIRM	6.38	0.87	0.91
Family Typology			
- Cohesion subscale of FACES	4.57	1.40	0.70
- Adaptability subscale of FACE	-30.76	38.67	-0.66
Sibling Appraisal			
- Mood subscale of SPQ	7.25	4.19	-0.09
- Perception subscale of SPQ	-2.04	1.87	0.76
- Knowledge subscale of SPQ	13.81	1.10	0.65
Sibling Adaptation			
- Efficacy subscale of SCSI	10.51	11.24	0.31
- Frequency subscale of SCSI	16.89	16.87	0.15

Table 25
Loadings of Critical Indicators to Latent Variables

Latent Variable	z value of Loadings
Social Support	
- Support subscale of CHIP	4.12
- Communication subscale of CHIP	- 4.75
- Resource subscale of FIRM	2.61
Family Typology	
- Cohesion subscale of FACES	3.40
Adaptability subscale of FACE	4.00
Sibling Appraisal	
- Mood subscale of SPQ	8.20
- Perception subscale of SPQ	5.45
-Knowledge subscale of SPQ	6.41
Sibling Adaptation	
- Efficacy subscale of SCSi	5.98
- Frequency subscale of SCSi	5.96

* Loadings are LISREL estimates (see Table 27)

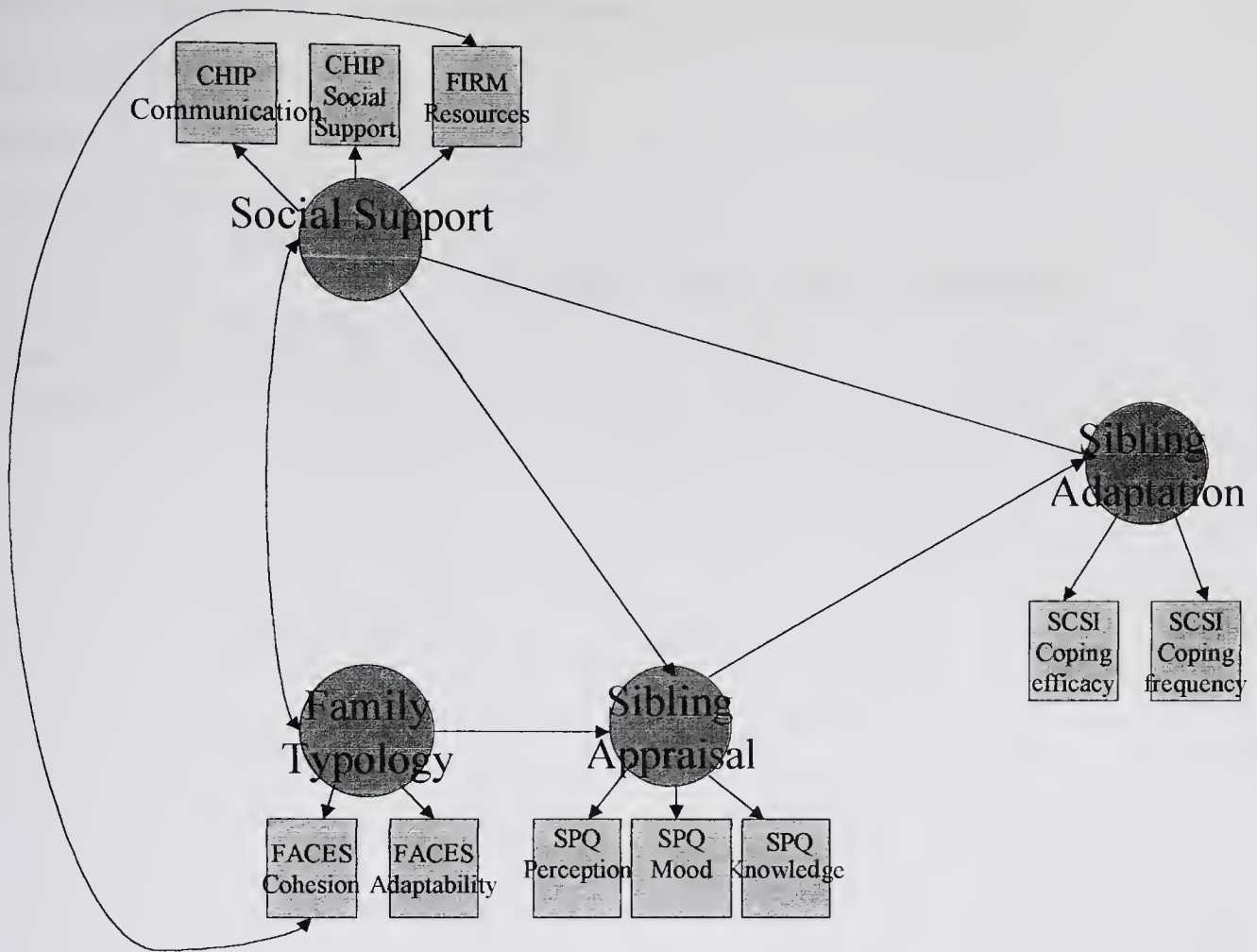


Figure 6. Final Structural Model

The final structural model (see Figure 6) resulted in one significant path from social support to sibling appraisal (t -value = 2.57). Consistent with the theoretical framework and literature review, social support has a direct effect on appraisal. The path from appraisal to sibling adaptation, although not statistically significant, was direct and positive. The effect of social support on sibling adaptation was indirect and positive suggesting that social support had a mediating effect (through sibling appraisal) on

sibling adaptation. Table 26 summarizes the relationships between the latent variables in the final structural model.

Table 26

Relationships between Latent Variables

Latent Variables	Total Effect	Direct Effect	Indirect Effect
Social Support/Sibling Appraisal	0.44	0.44	—
Social Support/Sibling Adaptation	0.21	0.14	0.07
Sibling Appraisal/Sibling Adaptation	0.15	0.15	—

Table 27 shows the maximum-likelihood estimates for the final model.

Table 27: *LISREL Estimates of Model Parameters*

Parameter	LISREL Estimate	Standard Error	Standardized Solution
$\gamma_1 (x_1)$	7.35	5.96	0.92
$\gamma_2 (x_2)$	5.95	5.98	0.83
$\gamma_3 (x_3)$	1.80	6.41	0.59
$\gamma_4 (x_4)$	1.94	5.45	0.49
$\gamma_5 (x_5)$	4.65	8.20	1.04
$\gamma_6 (y_1)$	4.39	3.40	0.55
$\gamma_7 (y_2)$	8.80	4.00	1.29
$\gamma_8 (y_3)$	0.81	4.12	0.47
$\gamma_9 (y_4)$	1.83	4.75	0.57
$\gamma_{10} (y_5)$	0.80	2.61	0.30

Conclusions

In summary, these results indicate that the main null hypothesis of no relationship among the variables has to be rejected, because there is a significant relationship between social support and sibling appraisal. There is a direct effect of appraisal on sibling adaptation. There are no relationships between family typology and sibling appraisal. Appraisal appears to be a mediating variable between social support and sibling adaptation.

CHAPTER 5: DISCUSSION

Introduction

Chronic illness in a family is an acknowledged stressful event. Type 1 diabetes, therefore, poses a myriad of challenges for the family, requiring considerable strength to enhance coping and adaptation. Families with effective organization and functioning can, and do, manage the illness and the development of the family with minimal difficulty. A resiliency framework uses concepts that humanize the experience and accompanying challenges and encourages optimal family functioning as well as the physical, emotional and psychological well being of all family members.

Coping strategies

Coping strategies are what the child does in contrast to resources the child has. Integral to the stress-coping process is the sibling's individual appraisal of the stressor, and the appraisal of one's own coping resources. This study approached the measurement of coping from the perspective that siblings of children with a chronic illness are confronted with a consistent set of demands related to daily management of type 1 diabetes and that these siblings come to form a relatively consistent pattern of coping with these demands.

Coping strategies include the child's attempt to change their perceptions of the situation as well as attempts to change the situation itself. Nurse researchers, consistent with the developmental perspectives, acknowledge that age, gender and developmental level play an important role in how siblings respond to the experience of living with a chronic illness (Van Riper, 2003). Furthermore, coping strategies must be learned,

although there seems to be a biological component based on tendencies to fight or to flee (Sinnema, 1991).

This study identified some of the same coping responses as Ryan (1988, 1989, 1990) and Sorenson (1990), plus some distinct responses not mentioned in the above studies. The results of the present study suggest that the coping strategies employed by the siblings of children with type 1 diabetes tend to fit into a few distinct categories based on the aggregates of specific responses (e.g. distraction, relaxation behaviors, cognitive behaviors, social support and spirituality). The results also revealed that, for the most part, the siblings rated the coping strategies that they chose to utilize as helpful to dealing with the stressors in their lives. It is interesting to note that the children did use behaviors in the social support domain quite frequently, and did rate them as effective. Likewise, as illustrated in the following section on structural equation modeling, there was a direct effect of the latent variable of social support on the latent variable of sibling adaptation.

Coping with illness-related stress may imply a variety of thoughts, emotions, and behaviors, such as positive thinking, physical exercise, distraction, spiritual behaviors and behavioral and emotional control. The means of meeting these objectives may involve both cognitive processes as well as the active manipulation of the environment. The other coping strategies most commonly employed by the siblings in this study (relaxation, cognitive behaviors, spirituality) were emotion-focused rather than problem-oriented. Whereas problem-oriented coping strategies are designed to change the situation, emotion-focused behaviors are not designed to change the stressor but rather to reappraise the situation in a more positive manner. These findings, offering a glimpse

into the sibling's reality, validated the results of previous research (Sorenson, 1990, Taylor, 1980, Walker, 1988) that the most common response to living with type 1 diabetes was to utilize coping strategies designed to help endure the stressor of living with the illness, rather than to try to change the situation.

The study of siblings of children with type 1 diabetes can make a considerable contribution to understanding the strengths and needs of the entire family. Families coping with type 1 diabetes are a population at risk. Consistent with Lazarus and Folkman's (1984) stress-coping theory for adults, children aged eight and above are capable of appraising the frequency and effectiveness of their own coping resources. In many cases, especially for children living with a chronic illness, stressors cannot be changed (Lazarus & Folkman, 1984). In these cases, distracting or avoidant behaviors may be the most appropriate coping strategies as they help the child adapt to the present situation. The identified stressor in this study was living with type 1 diabetes, an experience which qualifies as an enduring stressor. The data reveal that subjects in this study did rely on both distracting and avoidant behaviors to cope with living with type 1 diabetes suggesting that the siblings were aware that living with the daily management tasks of type 1 diabetes was to be a permanent part of their lives.

There were some interesting gender differences noted in this study that provide important information to those attempting to understand how children cope with living with type 1 diabetes in the family. Specifically, girls used more coping strategies than boys and found them more effective. Of the 13 coping strategy domains included in the frequency subscale of the SCS, girls used 6 of the coping strategies (social support domain, emotional domain, distraction domain, aggressive motor domain, spirituality

domain and relaxation domain) significantly more often. There were no coping strategy domains in the frequency subscale that were used significantly more often by boys than girls. Of the 13 coping strategy domains included in the efficacy scale of the SCSI, girls used 3 of the coping strategies (social support domain, spirituality domain and relaxation domain) significantly more often than boys. Likewise, there were no coping strategy domains in the efficacy subscale that were used significantly more often by boys than girls.

Curiously and contrary to other research on children and coping (Ryan, 1989,1990) there were no age specific differences noted with either the Frequency or Efficacy subscale of the SCSI in this study. One plausible explanation for this finding is that the sample in this study included siblings aged 8-14 years and the sub-samples were divided into those siblings aged 8-11 years and 12-14 years. Perhaps, there would have been significant differences had the sample included older adolescents (aged 15-18 years) as children aged 12-14 are still considered to be young adolescents (Davies, 1999). In addition, Peterson (1988) noted that a child's present ability to cope is likely to be influenced by the style of coping they already use. Therefore, these findings appear to support the need to assess the coping of children prior to teaching them coping strategies, as children seem to have different concepts of illness and intellectual development based on their age and developmental level (Burbach & Peterson, 1986).

Unfortunately, the cross-sectional design used in this study does not permit the researcher to examine the effects of the pileup of demands on the adaptation of siblings to living with a chronic illness. According to McCubbin (1989), it is extremely important to assess the pileup of demands in the case of studying the adaptation of a family member to

a chronic illness as the demands to the individual family members change over time. Robins (1983) noted that single dramatic life events are time-limited and differ from one's typical living situation. Although much of nursing research must be directed at helping children cope with major trauma, such as illness, death or divorce of parents, there is a need to study the possible potentiating effects of superimposed daily hassles and associated coping resources related to living with a chronic illness.

Thus, there is support for the contention that children tend to take an active approach to the obstacles they face in their lives, bringing with them a variety of coping strategies upon which to avail. In conclusion, the implications of the present study for sibling intervention programs, consistent with previous research (Walker, 1988; Ryan-Wenger, 1990), are manifold. Providing information and education about type 1 diabetes is necessary but not sufficient on its own to promote successful adaptation to living with type 1 diabetes in the family. In addition to providing information and education, siblings may benefit from coping skills training programs. Intervention programs that teach siblings how to use more effective coping strategies and to improve their levels of social competencies may be beneficial. For example, improving the sibling's abilities to cope with inquisitive school friends by increasing their repertoire of social skills may help them cope more effectively with difficult questions.

These findings also suggest that sibling adaptation may be a function of the degree to which the sibling is able to maintain productive coping strategies that enable them to maintain a healthy perception of themselves as an integral part of the family unit. Data gleaned from this study provide important information regarding that which enhances healthy adaptation on the part of the siblings. Doubtlessly, interventional studies that

generate data describing coping behaviors that optimize sibling adaptation are warranted. Such interventions must address the sibling's perspective, and validate ways of matching interventions with the unique appraisals and coping efforts.

Appraisal

The manner in which a child behaves with respect to any situation tends to be in accord with how he or she perceives or appraises the particular situation (Knutson, 1965). According to The Resiliency Model of Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993), an individual's appraisal of an experience shapes the response, the thoughts, the emotions and/or the behaviors. Generally, it is believed that these thoughts, behaviors and/or emotions are modifiable if the individual can engage in alternative appraisals that are assumed to be under a person's control (Meichenbaum, 1991).

Assuming this, how a sibling adapts to the experience of living with type 1 diabetes in the family will be in accord with how he or she perceives that situation. In the face of an illness-induced family crisis demanding changes in rules and organization and patterns of functioning, the family members must appraise their past and future in effort to give meaning to the resulting changes in the family system. Over time, family members develop, shape, and attach value to a set of shared or accepted values, rules, goals, priorities, and expectations, which compose their unique appraisal and this appraisal can either facilitate or impede adaptation. The relationship between appraisal and adaptation has been discussed extensively by Lazarus and Folkman (1984). Lazarus's (1966) theoretical framework suggests that the appraisal of a situation affects how individuals cope as well as their emotional, physiological, and behavioral reactions to stressful experiences.

Data from previous studies (Gallo, Breitmayer, Knafl, & Zoeller, 1991; Hanson et al., 1992) are rich with evidence related the sibling's awareness of feeling a wide range of emotions within the illness experience including "scared", "sad", "bad", "worried", "jealous", "mad", and "hopeful". In the present study, data from the perception subscale clarified the question regarding which circumstances in the sibling illness experience lead to maladaptive behaviors and the data suggest that the siblings did, at times, feel jealous and/or mad. Many siblings did feel sad or worried that their brother or sister had diabetes. These emotions are natural in such circumstances and how the siblings cope with these emotions can lead to either adaptation or maladaptation. If the parent or nurse can recognize these emotions and help the sibling perceive the situation in a more positive manner, it is more likely that adaptation will ensue.

In concordance with the theory of symbolic interactionism, living with type 1 diabetes may be viewed as a crisis by one sibling and defined as a challenge by another sibling. The symbolic meaning of the illness experience as well as the sibling's repertoire of coping behaviors and problem-solving behaviors are variables that influence how a sibling perceives living with a brother or sister with type 1 diabetes. The data from the structural equation model suggest that children who appraise the illness experience as positive most of the time tend to adapt better to living with this illness. Consequently, children who rarely feel this way tend to have more problems with adaptation. If it can be demonstrated that particular coping strategies are directly related to the development of morbidity, perhaps labels of maladaptation can be attached to these behaviors. Such research has yet to be done.

According to Marcus (1999), some children seem uninterested in being provided with more than the cursory information. In other families, there may be an unspoken family rule about not asking questions. The siblings learn to sense those topics that are safe and learn to avoid the sensitive areas. Children are at different stages of readiness to hear about the details of their brother's or sister's illness and that confusion and anxiety can be avoided when the parents are willing to respond to questions as openly and honestly as possible. It has been suggested that information about the illness is a resource factor which enables children to make sense of the situation (Van Dongen-Melman & Sanders-Woudstra, 1986). Other researchers (Birenbaum, 1989; Ross-Alaomolki, Heinzer, Howard & Marszal, 1995) found that open communication increased coping and adaptation. This openness may facilitate the children's coping with the stress of and adaptation to living with type 1 diabetes in the family through increasing the sibling's knowledge of the disease. The results of this study reinforced the above notion that the siblings did feel a need for knowledge of diabetes and for the most part, felt that additional information would be beneficial.

The siblings of the children with type 1 diabetes have unique needs, desires and feelings that need to be identified and addressed. One of the effects of living with type 1 diabetes in the family is the dramatic shift in family dynamics related to the intense attention necessary to manage the diabetes. Such shifts in the family system can have a tremendous impact on the siblings of the children with diabetes (Marcus, 1999). Because the siblings are not the focus of this intense, daily attention the way their siblings with diabetes are, they may feel ignored and unimportant. Tremendous care and attention

needs to be given to this still very significant family member to ensure an environment they feel is safe, nurturing and receptive to a wide range of human emotions.

In conclusion, the findings from this question also suggest that increasing the siblings' knowledge and understanding of the illness is necessary but not sufficient on its own to promote successful adaptation to living with type 1 diabetes. It appears that that siblings have some difficulty understanding why the disease places such extra time upon the family system, but that the siblings do not feel personally affected by these demands. In addition to providing information and education, siblings may benefit from interventions to promote more effective coping strategies. Empathy for the child with diabetes, respect for the needs of the parents, and a cognitive understanding of the disease seem to permeate the sibling's responses. Only through an understanding of the sibling's perception of the illness experience, can one truly understand what the sibling understands, attempt to facilitate the sibling's development and promote healthy adaptation for the sibling and family. It seems invaluable to gain insights into the sibling's view of this situation to predict critical perceptions leading to maladaptive responses in such children. Further, such data could be utilized to develop nursing interventions on behalf of the siblings of children with type 1 diabetes.

Adaptation

Few would argue the complexity and challenges faced by a family with a child who has type 1 diabetes. Conceptualizing and operationalizing siblings' adaptation is complicated and often confusing. In many early studies of sibling adaptation (Cobb, 1958; Binger, 1969), outcome measures have been predominately negative, focusing particularly on measures of distress. Additionally, this earlier work had been primarily

influenced by traditional research models that focus on psychopathology or major dysfunctional behavior. According to Faux (1991), the increased risk of adjustment problems identified in earlier studies may be attributed to reliance on case studies and anecdotal reports, small convenience samples, lack of comparison groups, use of standardized measurement and maternal ratings of behavior. Therefore, the term adaptation needs to be clearly defined and conceptually analyzed in order to identify the critical attributes of the phenomenon.

Adaptation is viewed multidimensionally and includes mental health, social functioning and physical health (Thompson & Gustafson, 1996). The factor hypothesized to be primarily responsible for elevating the risk for developing psychosocial problems in children facing a crisis situation is stress. Siblings of children with type 1 diabetes may experience stress in their lives that emanates from living with a chronic illness in the family or from stressors associated with major life events, daily hassles, or developmental transitions. For example, the child with type 1 diabetes must be willing to adapt to a diet regimen, exercise pattern and insulin injections to maintain metabolic control. Consequently, the family members are called upon to modify their lifestyle in order to maintain the homeostasis within the family. Adaptation is said to have occurred if these changes restore a sense of equilibrium within the individual family members as well within the family system as a whole.

The nature and severity of adaptation problems as assessed in the present study do not form as bleak a picture as do some previous research studies on the topic (Menke, 1987; Breslau & Prabucki, 1987; Cohen, 1995). Iles (1979), for example, reported that the siblings had altered peer relationships and felt a loss of parental time and Taylor

(1980) reported that two-thirds of the siblings experienced of isolation, deprivation and inferiority. The majority of siblings in this study appeared to be adapting well with the major disruption in their lives occasioned by their brother or sister's illness and, at this stage, showed little evidence of serious detrimental effects on their emotional or behavioral functioning. Worthy of note is that, based on self-report, the percentage of siblings that scored in the depressed range was less than the average for the general population. This statement holds true for both age and gender groups. As described in the results section, only 4.7% of the siblings interviewed had scores in the depressed range using 16 as the cut-off CDI score for depression. According to Kovacs (1992), using a score of 16 on the CDI as a cut-off point for depression would identify almost 10% of the sample as depressed.

One possible explanation for the below than average scores on the CDI is that the experience of living with type 1 diabetes in the family becomes an opportunity for growth for the siblings. Previous studies have concluded that siblings do report positive experiences, such as increased empathy and compassion, as a result of living with a child with a chronic illness (Sahler & Carpenter, 1987; Faux, 1991). Perhaps internal coping strategies and problem-solving behaviors, social support and family resources play a role in the adaptation process. Efforts should be made to further explore the role of these variables on adaptation in future studies.

Recognition of the systemic impact of chronic medical illness in children is important in order to provide for family-centered hospital treatment interventions and proposals for enhancing the ability of health care professionals to meet the needs of the child with a chronic illness and their family. Future research might further address the

concept of adaptation as an outcome of the emotional experiences these siblings face, and examine how children learn to adapt in response to such extraordinary challenges.

Relationships among Family Typology, Social Support, Appraisal and Adaptation
Relationship between Family Typology and Sibling Appraisal. The family is the most important social context shaping and influencing the health and development of the child. Most, if not all, families experience many different kinds of normative and non-normative challenges over their lifetime that can leave them at risk and undermine their ability to maintain healthy functioning. In the present study, there was a negative relationship between family typology and sibling appraisal. Similarly, a number of other studies have not shown a positive relationship between family typology and sibling appraisal; in fact, Vance (1980) found that nearly twice as many siblings of children with nephrotic syndrome reported not having enough friends and time to play as compared with siblings in the matched group, and Taylor (1980) noted increased feelings of isolation, deprivation, or inferiority in two-thirds of the siblings interviewed. Spinetta and Deasy-Spinetta (1981) also found lower self-esteem, anxiety and depression in those siblings that perceived the family as experiencing conflict and less cohesion and Breslau and Prabucki (1987) found an increased risk of feelings of depression and isolation among the siblings of children with congenital disabilities living in a rigid and disengaged family structure.

However, the results of the work of Gallo and Szychliniski (2000) imply that an open family environment in which siblings are encouraged to talk and express their feelings may help promote a more positive appraisal to living with diabetes and a study by Wertlieb, Hauser and Jacobson (1986) supported the notion that social and recreational

family activities fostered a more positive appraisal of the illness experience in the siblings.

One explanation for the findings in the present study may be that a more cohesive and adaptive family contributes to better appraisal on the part of the child with the chronic illness and not necessarily the sibling without the illness. Perhaps it is that the cohesive families tend to focus more on the child with the illness and the sibling perceives this as neglectful to their needs. Likewise, perhaps the more adaptive families tend to “adapt” to the illness by focusing much of their time and attention to the daily tasks of managing diabetes, hence “adapting” well. This, too, can contribute to a perception of neglect on the part of the siblings who are not directly affected with the illness.

Second, a concern is raised regarding the measurement of family typology. While the low variance of family typology on adaptation might suggest that concept of family typology was not an important variable in predicting adaptation, alternative means to measure this construct to better capture the family’s structure might be considered in future studies.

Lastly, the present study did not control for the length of time since the diagnosis of type 1 diabetes or the age of the child with diabetes. It may be that families who have lived with the illness for a shorter period of time tend to spend more family time on disease management. Likewise, families with a younger child with diabetes may tend to be more involved with the diabetes regimen than families which have an older child or adolescent with diabetes (La Greca, 1998). Future studies are warranted to address these

issues to elicit more comprehensive information about family typology and sibling appraisal.

Relationship between Social Support and Sibling Appraisal. There was a significant positive relationship between social support and sibling appraisal. One plausible explanation may be that even though the initial intent of the family seeking social support was to help the child with the chronic illness, it may be that these social activities greatly influence the quality of life for the sibling, leading to a more positive appraisal of living with the chronic illness. In addition, the social activities may well help to deal with other family issues often experienced by families of children with a chronic illness (e.g. isolation, stigma) which in turn contributes to a more positive appraisal of the situation for the sibling. For example, many social activities intended for children with a chronic illness (support groups and summer camps) have a session especially devoted to the siblings of the child with the chronic illness. Perhaps, participation in social activities exposes the siblings to a wider world-view that removes them from the daily management tasks imposed by type 1 diabetes. Such interaction may well lead to a greater overall knowledge of the disease as well as a feeling of “being special”.

One cannot assume that most psychological adjustment and adaptation problems are due to the presence of a chronic illness in the family, neither can one assume that only families with a child with a chronic illness experience these problems (Pless & Roghmann, 1971). The data from the above studies, however, do show that a high proportion of families with a child with a chronic illness may be affected by the presence of chronic illness. The findings of this study as well as previous studies (Iles, 1979; Harder & Bowditch, 1982; Gallo & Szychliński, 2000) suggest that the siblings' ability to

tolerate stress and to perceive life changes as a positive experience may well influence adjustment and adaptation to chronic illness. It appears that the best index of the sibling response to the presence of a chronic illness is not necessarily the type or severity of the illness, rather the sibling's appraisal of the effects of the illness. Adjustment and adaptation to a chronic illness means adopting a perspective that the quality of life will be sufficient to merit the efforts (Tritt & Esses, 1988; Lubkin, 1986). An assessment of the siblings' appraisal of what constitutes a stressor, the resources and social support available to the sibling, as well as their definition of a meaningful life will help to determine how well the family will adapt to the chronic illness. Children's needs and responses can vary greatly based on their age and experience level (American Academy of Pediatrics, 2002).

The essence of understanding how a sibling copes with type 1 diabetes is to appreciate their appraisal of the illness and what exactly the illness means to them. Measurement of siblings' appraisals has been problematic because of the lack of standardized instruments (Sloper & White, 1996) and was addressed by Carpenter and Sahler (1991) with the development of the Sibling Perception Questionnaire (SPQ). The present study used this measurement instrument to measure the latent variable of sibling appraisal using the three subscales of the SPQ (Knowledge, Perception and Mood) as the critical indicators of the variable. However, while the effect of sibling appraisal on sibling adaptation was positive and direct, it was not a significant relationship. Once again, this may be due to problems with the measurement of the latent variables of appraisal and adaptation. Even though the SPQ is thought to be an improvement over earlier tools, the use of quantitative measures alone may not be able to capture a complete

picture of the child's appraisal of the illness experience. In fact, several researchers (Sloper & White, 1996; Adams, 1991) have used either a qualitative methodology or a triangulated approach. Future studies should be designed to examine the relationships between appraisal and adaptation with other well-validated measures of a sibling's functioning over a broad range of situations including academic performance, peer and family relationships, physical health and recreational activities.

Relationship between Social Support and Sibling Adaptation. The effect between social support and sibling adaptation in this study was both direct and indirect. With regard to a broader definition of family, there is a conceptual basis for expecting that extrafamilial factors, such as schools, neighborhoods and religious organizations, and the beliefs and values of the culture influence individual family members (Cummings, Davies and Campbell, 2000). Van Riper (2000) also found a significant relationship between both family resources and family communication with at least one critical indicator of sibling well-being in her study using the Resiliency Model as a theoretical framework.

Walker et al. (1992) conducted a Delphi study to describe the nursing behaviors or interventions that best facilitate the coping efforts of pediatric cancer patients, their parents and their siblings and Murray (2001) conducted a quantitative study to determine the sibling's and parent's perceptions of the nursing interventions that help the sibling adapt to the childhood cancer experience. Gallo (1988) noted that the nurse's role ranges from providing emotional support for parents and siblings, to providing practical help and information. The results of these studies showed that common sibling facilitative behaviors included open communication from the nurses, making the siblings feel special, encouraging consistent discipline for the patients and the siblings, and

encouraging visits to the hospital or the clinic. The CHIP instrument used in the present study did include items specific to the parent's perception of the social support offered by the health care team, but social support was not measured from the sibling's perspective. A future study is suggested to determine which nursing behaviors, specific to siblings of children with type 1 diabetes, are found to be most helpful to promote sibling adaptation.

Relationship between Sibling Appraisal and Adaptation. The results of this study indicate a positive and direct effect, but not significant relationship, between sibling appraisal and adaptation. In the final structural model the latent variable of sibling adaptation was measured exclusively by two critical indicators describing coping responses, namely the Frequency subscale of the SCSI and the Efficacy subscale of the SCSI. The CDI was also used as a critical indicator of sibling adaptation in the original model but was removed in the revised and final model as, based on the confirmatory factor analysis, it did not load well with the other variables.

There are several possible reasons that may explain these findings. First, a concern is raised regarding the measurement of coping in children. According to Gamble and McHale (1989), scale development for children's instruments has often proceeded with samples that are small and unrepresentative. Some items are based on the responses to hypothetical problems, while others reflect children's reports of efforts to cope with problems actually experienced. Further, much of the information resulting from some instruments is based on retrospective self-reports and may not represent a child's actual coping experience, but rather scripts of what they might do (Spiritio, Stark, & Williams).

Second, because the SCSI was developed 15 years ago, it does not include many coping strategies used by children at the present time, namely, electronic mail, video

games and cellular phone usage. According to the author of the SCSI, the instrument is in the process of an updating and revision (N.M. Ryan-Wenger, September, 2001, personal communication). Additionally, in the present study, the siblings were asked to respond to coping strategies specifically used to respond to the stressor of living with type 1 diabetes. However, the SCSI did not include items related to stressful events specific to the family life of a sibling of a child a chronic illness.

Third, the concept of adaptation is fraught with major logical, measurement, and pragmatic problems (Duquette, 1997). Because concepts are often abstract, the empirical references may demonstrate the occurrence of the concept itself. There is great diversity in the use of the concept; it is used variously as a quality, a trait, a process or as an outcome. There is little consensus on the definition of the term, standards for it application, or agreement on its role in explaining models and theories. In sum, these problems and inconsistencies in interpretation and measurement of adaptation raise concerns about its explanation of behavior and outcomes.

These problems with instrumentation and conceptualization might account, in part, for the nonsignificant relationship between appraisal and sibling adaptation in the present study. However, it is well documented that the nature and number of stressors experienced by siblings of children with a chronic illness and their appraisal of the situation, does play a central role in their overall daily functioning (Adams, 1991; Zeltzer et al., 1996; Van Riper, 2000). Documenting what constitutes stress or coping for these siblings will have implications not only for the development of theoretical frameworks, but also for the design of effective prevention and intervention efforts. Therefore, just as some researchers have successfully adapted family stress and coping models for

examining processes of adaptation to a chronic illness at the family level, future researchers may benefit from the development of theory and frameworks designed to better conceptualize the concept of adaptation in effort to understand the specific problems that siblings living with a chronic illness may face.

Appraisal as a Mediating Variable between Social Support and Adaptation. There is a mediating affect between social support and sibling adaptation though the latent variable of sibling appraisal as depicted in the final structural model. It appears from the findings of this study that the presence of social support may enable the sibling to have better intrapsychic function, thereby indirectly promoting adaptation. However, the measurement of both process and outcome seem to be a prerequisite to understanding the concepts of appraisal and adaptation. Therefore, further studies are needed to examine the temporal stability of the constructs included in the original study. If positive adaptation requires a previous positive appraisal, the degree of adaptation might be underestimated in a cross-sectional study. Future efforts should be directed at prevention or early intervention with these high-risk patients in effort to minimize future problems and to maximize their adaptation.

Every family can be described in terms of their strengths and weaknesses (Siegel & Silverstein, 1994). A chronic illness does not change the essentials of child development and children need to grow up in a nurturing environment in order to develop self-esteem, self-reliance, resiliency, and autonomy (Sinnema, 1991). The quality of family relationships is critical to the adaptation of all children in a family and an understanding of the process of adaptation of families with a child with a chronic illness is critical as

successful adaptation may prevent family problems and disease-related complications leading to maladaptation (Auslander, Bubb, Rogge & Santiago, 1993).

While not an original question of this study, it is interesting to speculate on the origin of these dysfunctional dynamics. It may be that, for some families, the burden of managing diabetes results in such a pile-up of demands that some families cannot adequately adapt to the challenges of the disease; this then leads to chronic stress that reinforces (Doherty & Campbell, 1988) maladaptive behaviors. This failure to adapt not only has the potential to bring immediate harm to individual family members personally, but unwittingly in time maladaptive behaviors can bring attention to the whole family. Dysfunctional family dynamics may retard the child's developmental progress and preclude identity formation. Should the developmental process be stopped or impeded, as it might if family dynamics are dysfunctional, maladaptation under the guise of acting out or behavioral difficulties may result. The challenge to health care professionals is to empower families to increase their resources and coping behaviors for managing the multiple sources of stressors, strains and daily hassles that compromise the ongoing demands of family outcomes (Patterson, 1995).

Children will be affected when a brother or sister has a chronic illness. What researchers should hope to achieve is an understanding of how the siblings perceive living with type 1 diabetes and what determines this appraisal. The results of this study illustrate the need for siblings to be provided with more information and a better understanding of the disease, its cause and its treatment, as well as positive coping strategies and problem-solving behaviors to deal with the stressors associated with living with diabetes. The presence of type 1 diabetes in the family may provide the stimulus to

mobilize untapped resources in the sibling and to strengthen them as an individual.

Living with a chronic illness often increases the sibling's sensitivity to others and alters their values and priorities in life. This in turn, can lead to personal growth and positive adaptation. Interventional programs aimed at increasing the sibling's knowledge and enhancing their appraisal of the illness, therefore, are necessary in order to help siblings adapt. Efforts to improve sibling adaptation can truly advance the focus of nursing research toward family-centered care.

The study examined the complex relationships between and among several complex constructs such as family typology, social support, sibling appraisal and sibling adaptation. Additionally, because these constructs were not likely to be captured by any one of these variables alone, the use of multiple indicators to define these variables was also indicated. The results of this study partially substantiate the resiliency framework. Because the onset of type 1 diabetes is a sudden rather than insidious event, it places the family in a crisis situation that requires immediate situation. Consistent with Reuben Hill's (1949) original definition of family crises, within the Resiliency Model a family in crisis does not carry the stigmatizing value judgment that the family has failed, is dysfunctional or in need of professional counseling (McCubbin & Patterson, 1983). Rather, a family crisis may be viewed as an expected, if not necessary, condition for a family to adapt to a difficult situation (McCubbin & McCubbin, 1993).

According to McCubbin and McCubbin (1993), the efficacy of the Resiliency Model, however, is best demonstrated in studies to include several critical variables in the Resiliency Model with the intention of determining which variables, in what causal order, help to explain the variables in family adjustment and adaptation. While this study

attempted to clarify the relationships of the major variables included in the Resiliency Model, the results did not entirely support the model. There was a significant relationship between social support and sibling appraisal. There was no effect of family typology on sibling appraisal. There was a direct effect of sibling appraisal on sibling adaptation. There was an indirect effect of social support on sibling adaptation mediated through sibling appraisal. Therefore, the model should be modified by additional variables such as resiliency and other measures of adaptive behaviors in attempt to better measure the concept of sibling adaptation.

Limitations

Much of the proposed research on chronic illness describes the needs of the children with the disease and their parents' response to the disease. A dearth of research attention has been given to the siblings of children with a chronic illness, and the little that is available describes the response of the siblings to the death of a child or to living with a terminal illness. While scant research attends those children whose siblings experience type 1 diabetes, the diagnosis of type 1 diabetes does require continuous adjustment and adaptation of the part of the siblings.

The investigation of the response of siblings to type 1 diabetes must address the difficult state of the art methodological problems in the assessment of child psychopathology as well as developmental competencies (Drotar & Crawford, 1985). The interpretation of any score on a standardized measure requires taking into account the purpose for which the information will be used (Waltz, Strickland & Lenz, 1991). Therefore, the researcher has to carefully select the data collection tools in light of the specific research questions and psychometric properties of the measures. According to

Drotar and Crawford (1985), the problem of research design concerning sibling psychological adaptation transcends the formidable problem of controlling for extraneous variables. The effects of living with a child with type 1 diabetes are inevitably confounded by a number of variables including siblings' direct experience with their ill sibling and indirect influences including the quality of family functioning. Also, there may be potential confounding variables that were not directly measured in this study that could explain the relationships under investigation.

In addition, research focusing on adaptation is faced with the hardships of separating cause and effect, locating measures to test adaptation and coping variables, simultaneously studying a large number of variables and defining a structural model capable of accurately summarizing the data. For these reasons, the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993) was used to organize variables thought to be related to adaptation into a conceptual framework that allows for the identification of factors predictive of successful adaptation. Perhaps the Resiliency Model would have been a better predictor of adaptation in a study with family adaptation as an outcome variable rather than sibling adaptation. Furthermore, one measurement instrument, the SPPC, was difficult for even the older children to comprehend, therefore the validity of these scores may be questionable. Future studies might well be enhanced by the use of measurement tools and a theoretical framework more specific to the siblings themselves.

Coping and adaptation research is largely conducted on convenience samples of individuals attending health care facilities. The participants in the present study were mainly recruited from the regional pediatric diabetes service at Yale-New Haven Medical

Center, which is a large teaching hospital. Patients and families who attend these institutions may be more aware of symptoms and stressors and consequently, their perception of the illness can significantly differ from non-users in important ways that can affect the conclusions. Furthermore, because participants are asked to respond retrospectively on adaptive behaviors, social desirability and recall bias can lead to additional measurement error. Additionally, the notion of temporal sequencing can affect the results of cross-sectional studies that investigate the effects of multiple variables.

Plausibly, the response of living with a sibling with type 1 diabetes may change over time. Initially, the siblings may have problems with coping, but the problems may lessen subsequently. Alternatively, some children may suppress their own needs only to have them arise later on to the surprise of both themselves and their family. Additionally, a cross-sectional design may be limited by its failure to identify the specific stressor for which the behaviors are reported (Frank, et al., 1998). In isolation, the cross-sectional data presented here may provide an incomplete picture of sibling adaptation. A follow-up longitudinal study to the present study may prove to be both necessary and beneficial in order to elicit more comprehensive information regarding sibling adaptation.

A related limitation to the present study involves the issue of temporal sequencing (Polit, 1996). Temporal sequencing becomes a problem when data for a causal model are all collected at the same time. For example, in the present model, the data measuring sibling appraisal was collected at the same time as the data measuring sibling adaptation. A direct effect between the two variables is difficult in cross-sectional studies to establish whether sibling appraisal preceded or followed sibling adaptation.

A critical problem of research investigating the psychological adaptation of children to a sibling's chronic illness relates to the issue of ruling out extraneous (non-illness) related influences (Drotar & Crawford, 1985). For the siblings in this study, the effects of living with a chronic illness might have been influenced by a variety of other factors including the sibling's prior relationship with the sibling, the direct experience with the child's disease management or the age and gender of the sibling. Because a sibling's adaptation to living with a chronic illness is achieved over time and in a social context that also changes, at any single point in time, there are several stressors and strains that contribute to a pile-up of demands that may affect a sibling's adaptation. This is particularly important in family situations involving a prolonged illness, such as caring for a child with a chronic illness (McCubbin & McCubbin, 1993). Finally, because the data collection for this study was completed in the family's home, the siblings were subjected to the inadequate controls inherent to conducting research in a home environment.

Nursing Implications

Living with type 1 diabetes creates increased family stress, requires constant adaptation by the family and poses a challenge to nurses to better understand and meet the needs of the patient as well as all members of the family. In the context of comprehensive care, the involvement of siblings can bring a unique view of family functioning that is important to the clinical management of the child with type 1 diabetes. Siblings often have a view of the family that is acutely observant and not always evident to other family members. To the extent that the healthy siblings are involved in the management and are given complete and accurate information regarding the nature of the

sibling's illness, their appraisal of the situation may be enhanced. Conversely, to the extent that the siblings are excluded and misinformed, they may experience stress, isolation and neglect. The data from this study suggest that social support may foster a more positive appraisal of living with type 1 diabetes. Additionally, the results demonstrated that appraisal appears to be a mediating effect between social support and sibling adaptation. These findings underscore the importance of keeping siblings knowledgeable about and involved with the care of the child with diabetes.

More profound barriers to the adaptation of siblings may result from the overall perception of families and health care workers that the siblings are adapting well when in fact, they may well be suffering in silence. Pediatric nurses, advanced practice pediatric nurses and pediatric nurse researchers are in an optimal position to involve siblings in the care of the child with diabetes. Such involvement can afford the nurse the opportunity to assess maladaptation behaviors as well as to foster coping strategies and behavior patterns that may enhance the sibling adaptation to type 1 diabetes.

Conclusions

Dealing with the daily management for a child with type 1 diabetes is unending. Since most of these children live at home, all family members are affected by the demands of a chronic illness. Awareness of the link between poorer management and poorer outcome might place additional stress on the families that may not be evident with some other childhood diseases (Marteau & Greene, 1984). Unlike many other childhood illnesses that may either improve with time or end with the death of the child, the severity of diabetes tends to increase as one moves along the illness trajectory.

Many individual characteristics of children, the illness involved and the family structure are examined in order to understand why some siblings adapt well while others do not. Sibling constellation factors, temperament and personality appear to play a role in sibling adaptation (Garmezy, 1993). This study suggests that siblings seem to adapt better when they perceive living with type 1 diabetes as a positive rather than a negative event, and when they utilize specific coping skills that enable them to have a more positive appraisal of the illness experience. Additionally, the present study suggests that social support may enable the siblings to have a more positive appraisal of the situation, which may indirectly help enhance adaptation.

The fact that many siblings of children with type 1 diabetes do not develop issues that dictate professional intervention may reflect their capacity to function effectively under stress. This does not, however, absolve health professionals from their responsibility to include siblings in both their practice and research endeavors. The nature of understanding how a sibling copes with the diagnosis of type 1 diabetes in a child is to appreciate their concept of diabetes; that is, what it means to them. It is only in

this manner that research can begin to make sense of the complex process of a sibling adapting to living with a chronic illness.

This study underscores the importance of how a child's perception of an experience can affect their response to the world. An understanding of the stressors and coping strategies as they occur in childhood from the child's actual experience and perspective might provide information for more effective promotion of sustained health and effective coping through adulthood. Further, this study has demonstrated that there is much to learn from the child who is able to appraise life's stressors as meaningful challenges, leading to adaptive rather than maladaptive behaviors.

Many siblings are positively responding to living with a child with type 1 diabetes, and their success should be the focus of current research so that appropriate interventions can be initiated. Few studies with an emphasis on adaptive behaviors are available in the literature and it is therefore of interest to investigate which factors potentiate or moderate resilient behaviors in siblings in response to type 1 diabetes. The majority of studies signify widespread recognition that adaptation must be studied within the context of normative development as well as deviant behavior, and that the sibling's unique appraisal of the situation and choice of coping strategies must be examined from the sibling's own perspective.

Additional research on sibling adaptation to type 1 diabetes might focus on the individual differences in sibling coping patterns and problem solving behaviors, ways to promote resilient behavior in children, the factors that contribute to psychological adaptation, and the evaluation of preventative interventions designed to enhance sibling

adaptation to a chronic illness. Such research has the potential of uniting theory development, research and clinical practice in an effort to optimize the care of children living with type 1 diabetes in the family.

References

- Achenbach, T. M. (1991). *Manual for the child behavior checklist*. Burlington: University of Vermont.
- Adams, R., Peveler, R. C., Stein, A., & Dunger, D. B. (1991). Siblings of children with diabetes: Involvement, understanding and adaptation. *Diabetic Medicine*, 8, 855-859.
- American Academy of Pediatrics. (2002). "*When Terrible Things Happen*" (Available from Johnson & Johnson Pediatric Institute, P.O. Box 140097, St. Louis, MO, 63114-9907).
- American Diabetes Association. Diagnosis and classification of diabetes mellitus. (2004). *Diabetes Care*, 27(suppl. 1): 1-10.
- American Diabetes Association. *Diabetes: 2001 Vital Statistics*. (2001). Alexandria, VA, American Diabetes Association.
- Anderson, B. & Auslander, W. (1980). Research on diabetes management and family: A critique. *Diabetes Care*, 3, 696-702.
- Anderson, J. C. & Gerbing, D. W. (1988). Structural equation modeling in practice: A review and recommended two-step approach. *Psychological Bulletin*, 103, 411-423.
- Atkins, R. & Amenta, M. (1991). Family adaptation to AIDS: A comparative study. *Hospice Journal*, 7, 71-78.
- Antonovsky, A. (1987). *Unraveling the mystery of health*. San Francisco: Jossey-Bass.

Auslander, W. F., Bubb, J., Rogge, M., & Santiago, J. V. (1993). Family stress and resources: Potential areas of intervention in children recently diagnosed with diabetes. *Health and Social Work, 18*, 101-113.

Austin, J. & Huberty, T. (1989). Revision of the Family APGAR for use by 8-year-olds. *Family Systems Medicine, 7*, 323-327.

Bene, E., & Anthony, J. (1978). *Manual for the Children's Version of the Family Relations Test*. Windsor: Nelson.

Bentler, P. M. (1990). Comparative fit indices in structural models. *Psychological Bulletin, 88*, 588-606.

Binger, C. M., Albin, A. R., Feuerstein, R. C., Kushner, J. H., Zoger, S., & Mikkelsen, C. (1969). Childhood leukemia: Emotional impact on patient and family. *New England Journal of Medicine, 280*, 414-418.

Birenbaum, L. (1989). The relationship between parent-sibling communication and coping of siblings with death experience. *Journal of Pediatric Oncology Nursing, 6*, 86-91.

Blumer, H. (1969). *Symbolic Interactionism*. New York: Harper & Row.

Bollen, K. A. (1993). *Testing structural equation models*. Newbury Park, California: Sage Publications.

Breslau, N. & Prabucki, K. (1987). Siblings of disabled children. Effects of chronic stress upon the family. *Archives of General Psychiatry, 44*, 1040-1046.

Brown, S. A. (1985). Diabetes and grief. *Diabetes Educator, 11*, 53-57.

Burbach, D. & Peterson, L. (1986). Children's concept of physical illness: A review and critique of the cognitive-development literature. *Health Psychology, 5*, 307-325.

- Burton, L. (1975). *The Family Life of Sick Children*. Routledge and Kegan Paul: London.
- Cairns, N., Clark, G. M., Smith, S. D., & Lansky, S. B. (1979). Adaptation of siblings to childhood malignancy. *Journal of Pediatrics*, 95, 484-487.
- Caldwell, S. M. & Pichert, J. W. (1985). Systems theory applied to families with a diabetic child. *Family Systems Medicine*, 3, 34-44.
- Captain, C. (1989). Family recovery from alcoholism: Mediating family factors. *Nursing Clinics of North America*, 24, 55-67.
- Carpenter, P. & Sahler, O. (1991). Siblings' perception and adaptation to childhood cancer: Conceptual and methodological considerations. In J. H. Johnson & S. B. Johnson (Eds.), *Advances in child health psychology* (pp. 193-205). Gainesville: FL: University of Florida Press.
- Cobb, B. (1958). Psychological impact of long illness and death of a child on the family circle. *Journal of Pediatrics*, 48, 746-751.
- Cohen, D., Freidrich, W., Jaworski, T., Copeland, D., & Pendergrass, T. (1995). Pediatric cancer: Predicting sibling adjustment. *Journal of Clinical Psychology*, 50, 303-319.
- Craft, M. J., Lakin, J. A., Opplinger, R. A., Clancy, G. M., & Vanderlinden, D. W. (1990). Siblings as change agents for promoting the functional status of children with cerebral palsy. *Developmental Medicine and Child Neurology*, 32, 1049-1057.
- Crain, A. J., Sussman, M. B. & Weil, W. B. (1966). Family interaction, diabetes and sibling relationships. *International Journal of Social Psychiatry*, 12, 35-43.

Cummings, E. M., Davies, P. T. & Campbell, S. B. (2000). Application of developmental psychopathology: Parental depression, families and children's development. In E. M. Cummings, P. T. Davies & S. B. Campbell (Eds.). *Developmental psychopathology: Parental depression, families, and children's development* (pp. 299-340). New York: The Guilford Press.

Curran, D. (1983). *Traits of a healthy family*. Minneapolis: Winston.

Daniels, D., Miller, J. J., Billings, A. G., & Moos, R. H. (1986). Psychosocial functioning of siblings of children with rheumatic disease. *The Journal of Pediatrics*, 109, 379-383.

Daniels, D., Miller, J. J., Billings, A. G., & Moos, R. H. (1987). Psychosocial risk and resistance factors among children with chronic illness , healthy siblings, and healthy controls. *Journal of Abnormal Child Psychology*, 15, 295-308.

Danielson, C., Hamel-Bissell, B., & Winstead-Fry, P. (1993). *Families, health and illness. Perspectives on coping and intervention*. St.Louis: Mosby.

Davies, D. (1999). *Child development: A practitioner's guide*. New York: Guilford Press.

Deatrick, J. & Knafl, K. (1990). Management behaviors: Day-to-day adjustments to childhood chronic conditions. *Journal of Pediatric Nursing*, 7, 15-22.

Deatrick, J. & Knafl, K. & Walsh, M. (1988). The process of parenting a child with a disability. Normalization through accommodations. *The Journal of Advanced Nursing*, 13, 15-21.

Diabetes Control and Complications Trial Research Group. (1993). Effect of intensive diabetes treatment on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine*, 329, 435-459.

Doherty, W. J. & Campbell, T. L. (1988). *Families and health*. Beverly Hills, CA: Sage Publications.

Duquette, A. M. (1997). Adaptation: A concept analysis. *Journal of School Nursing*, 13, 30-33.

Drotar, D., & Crawford, P. (1985). Psychological adaptation of siblings of chronically ill children: Research and practice implications. *Developmental and Behavioral Pediatrics*, 6, 355-362.

Ekoe, J. M., Zimmet, R., & Williams, R. (2001). *The Epidemiology of Diabetes: An International Perspective*. West Sussex, England: Wiley & Son.

Emmons, C. L. (1992). *School development in an Inner city: An analysis of factors selected from Cromer's program using latent variable structural equation modeling*. Unpublished doctoral dissertation, University of Connecticut, Storrs.

Evans, C. A., Stevens, M., Cushway, D., & Houghton, J. (1992). Sibling response to cancer: A new approach. *Child: Care, Health and Development*, 18, 229-244.

Eysenck, H. J., & Eysenck, S. B. (1981). *Manual for the Eysenck Personality Questionnaire*. Kent: Hodder and Stoughton.

Faux, S. A. (1985). Parental-child rearing practices as perceived by the siblings and mothers of chronically impaired children. In K. King, E. Prodrick, & B. Bauser (Eds.). *Proceedings: 10th National Research Conference: Nursing Research, Science for Quality Care*. (308-314). Toronto, Canada: University of Toronto Press.

Faux, S. A. (1991). Sibling relationships in families of congenitally impaired children. *Journal of Pediatric Nursing*, 6, 175-184.

Fawcett, J. (1995). *Analysis and evaluation of conceptual models of nursing* (3rd ed). Philadelphia: F.A. Davis.

Ferrari, M. (1984). Chronic illness: Psychological effects on siblings. *Journal of Child Psychology and Psychiatry*, 3, 459-476.

Fielding, D., Moore, B., Dewey, M., Ashley, P., McKendrick, T., & Pinkerton, P. (1985). Children with end-stage renal failure: Psychological effects on patients, siblings and parents. *Journal of Psychosomatic Research*, 29, 457-465.

Finch, A., Saylor, C., Edwards, G., & McIntosh, J. (1987). Children's Depression Inventory. Reliability over repeated administrations. *Journal of Clinical Child Psychology*, 16, 339-341.

Furman, R. (1964). Death and the young child: Some preliminary considerations. *Psychoanalysis and Study of Children*, 19, 321-333.

Furman, W. & Burhmester, D. (1985). Children's perceptions of the qualities of sibling relationships. *Child Development*, 56, 448-461.

Gallo, A. M. (1988). The special sibling relationship in chronic illness and disability: Parental communication with well siblings. *Holistic Nursing Practice*, 2, 28-37.

Gallo, A. M., Breitmayer, B. J., Knafl, K., & Zoeller, L. H. (1991). Stigma in childhood chronic illness. *Pediatric Nursing*, 17, 21-25.

Gallo, A. M., & Szychlinski, C. (2000). Self-concept and satisfaction with family functioning in healthy siblings of children with diabetes, asthma, and healthy children. Family Research Conference, (July, 2000). University of Illinois, Chicago.

Gamble, W. & McHale, S. (1989). Coping with stress in sibling relationships: A comparison of children with disabled and non-disabled siblings. *Journal of Applied Developmental Psychology*, 10, 353-373.

Gardner, N. (1998). Emotional and behavioral difficulties in children with diabetes: A controlled comparison with siblings and peers. *Child: Care, Health and Development*, 14, 115-128.

Garmezy, N., Masten, A. S., & Tellegen, A. (1984). The study of stress and competence in children: A building block for developmental psychopathology. *Child Development*, 55, 97-111.

Gath, A. (1972). The mental health of siblings of congenitally abnormal children. *Journal of Child Psychology and Psychiatry*, 13, 211-218.

Gath, A., & Gumley, D. (1987). Retarded children and their siblings. *Journal of Child Psychology & Psychiatry*, 28, 715-730.

Gilliss, C. (1991). Family nursing research, theory and practice. *Image*, 23, 19-22.

Glick, I. A., Clarkin, J. F., & Kessler, D. R. (1987). *Martial and Family Therapy* (3rd ed.). Orlando, FL: Grune & Stratton.

Hagan, J. W., Barclay, C. R., Anderson, B. J., Feeman, D. J., Segal, S. S., Bacon, G., Goldstein, G. W. (1990). Intellective functioning and strategy use in children with insulin-dependent diabetes. *Child Development*, 61, 1714-1727.

Haggarty, R. J. (1986). Stress and illness in children. *Bulletin of the New York Academy of Medicine*, 62, 707-718.

Hanson, C. L., Henggeler, S. W., Harris, M. A., Cigrang, J. A., Schinkel, A. M., Rodrigue, J. R. & Klesges, R. C. (1992). Contributions of sibling relations to the adaptation of youths with insulin-dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology*, 60, 104-112.

Harder, L & Bowditch, B. (1982). Siblings of children with cystic fibrosis: Perceptions of the impact of the disease. *Children's Health Care*, 10, 116-120.

Harter, S. (1979). *Manual: Perceived competence scale for children*. Denver: University of Denver.

Harter, S. (1982). The perceived competence scale for children. *Child Development*, 53, 87-97.

Harter, S. (1985). *Manual for the self-perception profile for children*. Denver: University of Denver.

Hayduk, L. A. (1987). *Structural equations modeling with LISREL: Essentials and advances*. Baltimore, MD: John Hopkins University Press.

Hill, R. (1949). *Families under stress*. New York: Harper & Row.

Horowitz, W. & Kazak, T. (1990). Family adaptation to childhood cancer: sibling and family system variables. *Journal of Clinical Child Psychology*, 19, 221-228.

- Hoyle, R. H. (1995). *Structural equation modeling: Concepts, issues and applications*. Thousand Oaks, CA: Sage Publications.
- Iles, J. (1979). Children with cancer: Healthy siblings' perceptions during the illness experience. *Cancer Nursing*, 2, 371-377.
- Jöreskog, K. G. & Sörbom, D. (1979). *Advances in factor analysis and structural equation models*. Cambridge, Massachusetts: Abbot Books.
- Jöreskog, K. G. & Sörbom, D. (1996). *LISREL 8: User's reference Guide* (2nd ed.). Chicago, Illinois: Scientific Software International.
- Kager, V. A., Holden, E. W. (1992). Preliminary investigation of the direct and moderating effects of family and individual variables on the adjustment of children and adolescents with diabetes. *Journal of Pediatric Psychology*, 17, 491-502.
- Kaufman, F. R., & Halvorson, M. (1999). New trend in managing type 1 diabetes. *Contemporary Pediatrics*, 16, 112-123.
- Kenny, D. A. (1979). *Correlation and causality*. New York: Wiley Interscience.
- Knutson, A. (1965). *The individual, society and health*. New York: Russell Sage Foundation.
- Koch-Hattem, A. (1986). Siblings' experience of pediatric cancer: Interviews with children. *Health and Social Work*, 11, 107-111.
- Kosciulek, J., McCubbin, H., & McCubbin, M. (1993). A theoretical framework for adaptation to head injury. *Journal of Rehabilitation*, 35, 40-45.
- Kovacs, M. (1985). The children's depression inventory (CDI). *Psychological Bulletin*, 21, 995-998.

Kovacs, M. (1992). *Children's Depression Inventory (CDI) Manual*. Toronto, Ontario: Multi-Health Systems, Inc.

Kramer, R. (1981). Living with childhood cancer: Healthy siblings' perspective. *Issues in Comprehensive Pediatric Nursing*, 5, 155-165.

La Greca, A. M. (1998). It is all in the family responsibility for diabetes care. *Journal of Pediatric Endocrinology*, 11, 379-385.

Lavee, Y., McCubbin, H. I. & Patterson, J. M. (1985). The Double ABCX Model of Family Stress and Adaptation: An empirical test by analysis of structural equations with latent variables. *Journal of Marriage and the Family*, 11, 811-825.

Lavee, Y., McCubbin, H. I. & Olson, D. H. (1987). The effect of stressful life events and transitions on family function and well-being. *Journal of Marriage and the Family*, 49, 857-873.

Lavigne, J. V., Traisman, H. S., Marr, T. J., & Chasnoff, I. J. (1982). Parental perceptions of the psychological adjustment of children with diabetes and their siblings. *Diabetes Care*, 5, 420-426.

Lavigne, J. V. & Faier-Routman, J. (1993). Correlates of psychological adjustment to pediatric physical disorders: A meta-analytic review and comparison with existing models. *Developmental and Behavioral Pediatrics*, 14, 117-123.

Lavigne, J. V. & Ryan, M. (1979). Psychologic adjustment of siblings of children with chronic illness. *Pediatrics*, 63, 616-627.

Lazarus, R. S. (1966). *Psychological stress and the coping process*. New York: McGraw-Hill.

Lazarus, R. S. & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer.

Leonard, B. J. (1991). Siblings of chronically ill children: A question of vulnerability versus resilience. *Pediatric Annals*, 20, 501-506.

Leonard, B. J., Skay, C. L., & Rheinberger, M. M. (1998). Self-management development in children and adolescents with diabetes: The role of maternal self-efficacy and conflict. *Journal of Pediatric Nursing*, 13, 224-233.

Lubkin, L. M. (1986). *Chronic illness, impact and interventions*. Boston: Jones & Bartlett.

McCubbin, H. I. (1995). Resiliency in African-American families: Military families in foreign environments (FIRA-M). In H. I. McCubbin, A. Thompson, & M.A. McCubbin (1996). *Family assessment: Resiliency, coping and adaptation. Inventories for research and practice*. (pp. 843-864). Madison: University of Wisconsin Systems.

McCubbin, H. I., Comeau, J., & Harkins, J. (1981). Family Inventory of Resources for Management (FIRM). In H. I. McCubbin, A. Thompson, & M.A. McCubbin (1996). *Family assessment: Resiliency, coping and adaptation: Inventories for research and practice*. (pp. 307-324). Madison: University of Wisconsin Systems.

McCubbin, H. I. & Patterson, J. (1981). *Systematic assessment of family stress, resources, and coping: Tools for research, education and clinical intervention*. St. Paul, MN: Department of Family Social Science.

McCubbin, H. I., McCubbin, M. A., Nevin, R., & Cauble, A. E. (1983). Coping-Health Inventory for Parents (CHIP). In H. I. McCubbin, A. Thompson, & M.A. McCubbin (1996). *Family assessment: Resiliency, coping and adaptation: Inventories for research and practice*. (pp. 407-454). Madison: University of Wisconsin Systems.

McCubbin, H. I., McCubbin, M. A., Patterson, J., Cauble, A. E., Wilson, L., & Warwick, W. (1983). CHIP-Coping-Health Inventory for Parents: An assessment of parental coping patterns in the care of a chronically ill child. *Journal of Marriage and Family*, 45, 359-370.

McCubbin, H. I. & Patterson, J. (1983). The family stress process: The Double ABCX Model of adjustment and adaptation. In H. I. McCubbin, A. Cauble, & J. Patterson (Eds.). *Advances and developments in family stress theory and research*. (pp. 7-37). New York: Haworth.

McCubbin, H. I., & Thompson, A. (1987). *Family assessment inventories for research and practice*. (pp. 143-207). Madison, WI: University of Wisconsin-Madison.

McCubbin, H. I. & Thompson, A. (1991). *Balancing work and family life on Wall Street: Stockbrokers and families coping with economic instability*. Edina, MN: Burgess International Group.

McCubbin, M. A. (1984). Nursing assessment of coping with cystic fibrosis. *Western Journal of Nursing Research*, 6, 407-422.

McCubbin, M. A. (1989). Family stress and family strengths: A comparison of single-and two parent families with handicapped children. *Research in Nursing and Health*, 12, 101-110.

McCubbin, H. I. & McCubbin, M. A. (1987). Family stress theory and assessment: The T-Double ABCX Model of family adjustment and adaptation. In H. I. McCubbin & A. I. Thompson (Eds.) *Family Assessment for research and practice*. Madison: University of Wisconsin-Madison.

McCubbin, M. A., McCubbin, H. I. (1989). Theoretical orientations to family stress and coping. In C. R. Figley (Ed.) *Treating stress in families*. New York: Brunner.

McCubbin, M. A., McCubbin, H. I., & Thompson, A. (1987). Family problem solving, life-style related variables. *Nursing Research*, 34, 357-361.

McCubbin, M. A., & McCubbin, H. I. (1993). Families coping with illness: The resiliency model of family stress, adjustment, and adaptation. In C. Danielson, B. Hamel-Bissel, & P. Winstead-Fry (Eds). *Families: Health and illness, perspectives on coping* (pp. 20-64). St. Louis, MO: Mosby.

MacCullum, R. C., Browne, M. W. & Sugawara, H. M. (1996). Power analysis and determination of sample size for covariance structure modeling. *Psychological Methods*, 1, 130-149.

Maffeo, R. (1997). Helping families cope with type 1 diabetes. *American Journal of Nursing*, 97, 36-39.

Marcus, I. D. (1999). Equal time for siblings. *Diabetes Self-Management*, 6, 74-78.

Martinson, I. M., Gilliss, C., Colaizzo, D. C., Freeman, M., & Bossert, E. (1990). Impact of childhood cancer on healthy school-age siblings. *Cancer Nursing*, 13, 183-190.

Masten, A. S., Garmezy, N., Tellegen, A., Pellagrini, D. S., Larkin, K., & Larsen, A. (1988). Competence and stress in school children: The moderating effects of individual and family qualities. *Journal of Child Psychiatry and Psychology*, 29, 745-764.

Maruyama, G. M. (1998). *Basics of structural equation modeling*. Thousand Oaks, CA: Sage Publications.

Meichanbaum, D. (1991). Stress innovation training: A 20 year update. In R. Woolfolk and P. Lehrer (Eds.). *Principles and practices of stress management* (pp. 205-216). New York: Guilford Press.

Mengel, M. B., Lawler, M. K., Volk, R. J., Viviani, N. J., Dees, M. S., & Davis, A. B. (1992). Parental stress response within a family context: Association with diabetic control in adolescents with IDDM. *Family Systems Medicine*, 10, 395-404.

Menke, E. (1987). The impact of the child's chronic illness on school-aged siblings. *Children's Health Care*, 15, 132-140.

Moos, R. H., & Moos, B. S. (1986). *Family environmental scale manual*. Palo Alto, CA: Consulting Psychologists Press.

Murata, J. (1994). Family stress, social support, violence and sons' behavior. *Western Journal of Nursing Research*, 16, 154-168.

Murray, H. A. (1943). *Thematic apperception test*. Cambridge: Harvard University Press.

Murray, J. S. (2001). Social support for school-age siblings of children with cancer: A comparison between parent and sibling perceptions. *Journal of Pediatric Oncology Nursing*, 18, 90-104.

Nelson, W., & Politano, P. (1990). Children's Depression Inventory: Stability over repeated administration in psychiatric children. *Journal of Clinical Child Psychology*, 19, 254-256.

Newby, N. (1996). Chronic illness and the family life cycle. *Journal of Advanced Nursing*, 23, 786-791.

Norris, A. E. (1997). Structural Equation Modeling. In B. Munro (Ed.). *Statistical methods for health care researchers*. Philadelphia: Lippincott-Raven Publishers.

Northam, E., Anderson, P., Adler, R., Werther, G., & Warne, G. (1996). Psychosocial and family functioning in children with insulin-dependent diabetes at diagnosis and one year later. *Journal of Pediatric Psychology*, 21, 699-717.

Olsen, D., McCubbin, H., Barnes, H., Larsen, A., Muxen, M., & Wilson, M. (1983). *Families: What makes them work*. Beverly Hills, CA: Sage Publications.

Olsen, D., Larsen, A., & McCubbin, H. (1985). Family Strengths. In D. Olsen, H. McCubbin, H. Barnes, A. Larsen, A. Muxen. & M. Wilson (Eds.). *Family inventories*. Minneapolis: University of Minnesota.

Olsen, D., Portner, J., & Bell, R. Q. (1978). FACES II. Family adaptability and cohesion scales. *Family Social Science*. St. Paul, Minnesota: University of Minnesota.

Olson, D., Russell, C., & Sprenkle, D. (1989). Circumplex Model of Family Systems VIII: Family assessment and intervention. In D. H. Olson (Ed). *Circumplex Model: Systematic assessment and treatment of families* (pp. 7-49). New York: Haworth Press.

Patterson, J. M., McCubbin, H. I. & Warwick, W. (1990). The impact of family functioning on health changes in children with cystic fibrosis. *Social Science Medicine*, 31, 159-164.

Patterson, J. M. (1995). Promoting resilience in families experiencing stress.

Pediatric Clinics of North America, 42, 47-63.

Patterson, J. M. & McCubbin, H. I. (1983). Chronic illness: Family stress and coping. In C. R. Figley & H. I. McCubbin (Eds.). *Stress and the family: Coping with catastrophe* (pp.21-36). New York: Brunner.

Peterson, L. (1988). Coping by children undergoing stressful medical procedures: Some conceptual, methodological and therapeutic issues. *Journal of Clinical and Consulting Psychology*, 57, 300-387.

Piers, E. V., & Harris, D. B. (1969). *The Piers-Harris Children's Self-Concept Scale*. Nashville: Counselor Recordings and Tests.

Pineyard, B. J. (1983). Siblings of children with myelomeningocele: Examining their perceptions. *Maternal Child Nursing Journal*, 12, 61-70.

Pless, I. B. & Roghmann, K. J. (1971). Chronic illness and its consequences: Observations based on three epidemiologic surveys. *The Journal of Pediatrics*, 79, 351-359.

Polit, D. (1996). *Data analysis and statistics*. Stamford, CT: Appleton & Lange.

Reiss, D. (1967). Individual thinking and family interaction. *Archives of General Psychiatry*, 16, 80-92.

Rigdon, E. (1995). A necessary and sufficient identification rule for structural equation models estimated in practice. *Multivariate Behavioral Research*, 30, 359-383.

Robins, N. L. Some methodological problems and research directions in the study of the effects of stress on children. In N. Garnezy & M. Rutter (Eds.). *Stress, coping and development in children* (pp.335-346). New York: McGraw-Hill.

Ross-Alaomolki, K., Heinzer, M. M., Howard, R., & Marszal, S. (1995). Impact of childhood cancer on siblings and family: Family strategies for primary care. *Holistic Nursing Practice*, 9, 66-75.

Rutter, M., Tizard, J., & Whitmore, K. (1970). *Education, health and behavior*. London: Longman.

Ryan, N. M. (1988). The stress-coping process in school-age children: Gaps in the knowledge needed for health promotion. *Advances in Nursing Science*, 11, 1-12.

Ryan, N. M. (1989). Stress-coping strategies identified from school age children's perspective. *Research in Nursing and Health*, 12, 111-122.

Ryan-Wenger, M. N. (1990). Development and psychometric properties of the Schoolagers' Coping Strategies Inventory. *Nursing Research*, 39, 344-349.

Sahler, O. J., & Carpenter, P. J. (1987). Developmental differences among siblings' perceptions of the pediatric cancer experience. *Journal of Developmental and Behavioral Pediatrics*, 8, 121-138.

Siegel, B., & Silverstein, S. (1994). *What about me? Growing up with a developmentally sibling* (pp. 40-70). New York: Plenum Press.

Sinnema, G. (1991). Resilience among children with special health-care needs and their families. *Pediatric Annals*, 20, 483-486.

Skyler, J. S. (1997). Relationship of glycemic control to diabetes complications. In D. Porte & R.S. Sherwin (Eds.), *Ellenberg & Rifkin's Diabetes Mellitus* (5th Ed.) (pp. 1235-1254). Stamford, CT: Appleton & Lange.

Sloper, P., & White, D. (1996). Risk factors in the adjustment of siblings of children with cancer. *Journal of Child Psychology and Psychiatry*, 37, 597-607.

Smucker, M. R., Craighead, W. F., Craighead, I. W., & Green, B. J. (1986).

Normative and reliability data for the Children's Depression Inventory. *Journal of Abnormal Child Psychology*, 14, 25-29.

Snaith, R. P., Bridge, G. W., & Hamilton, M. (1977). *The Leeds Scales for the Self-Assessment of Anxiety and Depression Behavior*. Barnstable: Psychological Test Publication.

Sorenson, E. S. (1990). Children's coping responses. *Journal of Pediatric Nursing*, 5, 259-267.

Sorenson, E. S. (1993). *Children's stress and coping: A family perspective*. New York: Guilford Press.

Spinetta, J. & Deasy-Spinetta, P. (1981). The sibling of the child with cancer. In J. Spinetta & P. Deasy-Spinetta (Eds.). *Living with childhood cancer* (pp.294-297). St. Louis: Mosby.

Spiritio, A., Stark, L., & Williams, C. (1988). Development of a brief coping checklist for use with the pediatric populations. *Journal of Pediatric Psychology*, 13, 555-574.

SPSS for Windows: Release 7.5.1, Standard Version. (1996). Chicago, Illinois.

Stein, R. & Jessop, D. (1982). A non-categorical approach to chronic childhood illness. *Public Health Reports*, 97, 354-362.

Steinglass, P., & Horan, M. E. (1987). Families and chronic medical illness. *Journal of Psychotherapy and the Family*, 3, 127-142.

Stinnett, N. (1979). In search of strong families. In N. Stinnett, B. Chesser, & J. Defrain (Eds.). *Building family strengths* (pp. 257-274). Lincoln, NE: University of Nebraska Press.

Tabachnick, B., & Fidell, L. S. (1997). *Using Multivariate Statistics* (3rd ed.). New York: Harpers Collins Publisher.

Taylor, S. C. (1980). The effects of chronic childhood illnesses upon well siblings. *Maternal Child Nursing Journal*, 9, 109-116.

Taylor, E., Fuggle, P., & Charman, T. (2001). Well siblings psychological adjustment to chronic physical disorder in siblings: How important is maternal awareness of the attitudes and perceptions? *Journal of Child Psychology and Psychiatry*, 42, 953-962.

Tew, B. & Laurence, K. M. (1973). Mothers, brothers, and sisters of patients with spina bifida. *Developmental Medicine and Child Neurology*, 15, (suppl. 29), 69-76.

Thompson, R. J. & Gustafson, K. E. (1996). *Adaptation to chronic childhood illness*. American Psychological Association: Washington D.C.

Tritt, S. G. & Esses, L. M. (1988). Psychosocial adaptation of siblings of children with chronic mental illness. *American Journal of Orthopsychiatry*, 58, 211-220.

Van Dongen-Melman, J. & Sanders-Woudstra, J. (1986). Psychosocial aspects of childhood cancer: A review of the literature. *Journal of Child Psychology and Psychiatry*, 27, 145- 180.

Van Riper, M. (2000). Family variables associated with well-being in siblings of children with Down syndrome. *Journal of Family Nursing*, 6, 267-286.

Van Riper, M. (2003). The sibling experience of living with childhood chronic illness and disability. *Annual Review of Nursing Research*, 21, 279-302.

Vance, J.C., Fazan, L. E., Satterwhite, B., Pless, I. B. (1980). Effects of nephritic syndrome on the family: A controlled study. *Pediatrics*, 65, 948-955.

Varnl, J. W., Katz, E. R., Colegrove, R., & Dolgin, M. (1996). Family functioning predictors in children with newly-diagnosed cancer: a prospective analysis. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 37, 321-328.

Wagner, J. A., Scholl, R. A., & Gipson, M. T. (1998). Development of a scale to measure adherence to self-monitoring of blood glucose with latent variable measurement. *Diabetes Care*, 21, 1046-1051.

Walker, C. (1988). Stress and coping in siblings of childhood cancer patients. *Nursing Research*, 37, 208-212.

Walker, C., Adams, J., Curray, D., Guttuso, J., Gleason-Morgan, D., Hinds, P., Kramer, R., Panzarella, C., Vogel, R., Weekes, D., & Wright, P (1992). A Delphi study of pediatric oncology nurses' facilitative behavior. *Journal of Pediatric Oncology Nursing*, 10, 126-132.

Waltz, C. F., Strickland, O. L., & Lenz, E. R. (1991). *Measurement in Nursing Research* (2nd ed.) (pp. 286). Philadelphia: F. A. Davis Co.

Wertleib, D., Hauser, S. T., & Jacobson, A. M. (1986). Adaptation to diabetes: Behavior symptoms and family context. *Journal of Pediatric Psychology*, 11, 463-479.

Whitchurch, G. G. & Constantine, L. L. (1993). In P.G. Boss, W. J. Doherty, R. LaRossa, W. R. Schumm, & S. K. Steinmetz (Eds.), *Systems theory. Sourcebook of family theories and methods* (pp. 325-352). New York: Plenum Press.

Williams, P. (1997). Siblings and pediatric chronic illness: A review of the literature. *International Journal of Nursing Studies*, 14, 312-323.

Williams, P., Williams, A., Hanson, F. Graff, C., Ridder, L., & Curry, H. (1999). Maternal mood, family functioning, and perceptions of social support, self-esteem, and mood among siblings of chronically ill children. *Children's Health Care*, 28, 297-310.

Williams, P., Hanson, S., Karlin, R., Ridders, L., Liebergen, A., Olson, J., Barnard, M. & Tobin-Rommelhart, S. (1997). Outcomes of a nursing intervention for sibling of chronically ill children: A pilot study. *Journal of the Society of Pediatric Nurses*, 2, 127-137.

Zelter, L. K., Dolgin, M. J., Sahler, O. J., Roughmann, K., Barbarin, O. A., Carpenter, P. J., Copeland, D. R., Mulhern, R. K., Sargent, J. R. (1996). Sibling adaptation to childhood cancer collaborative study: Health outcomes of siblings of children with cancer. *Medical and Pediatric Oncology*, 27, 98-107.

Demographic Data

Birthdate: _____ Age _____ Code _____

Sex: Male _____ Female _____

Race/Ethnicity: Caucasian _____ African American _____ Hispanic _____

Grade in school: _____

How many children are in the family? _____

What is the birth order of this child?

First born.....	1
Second born.....	2
Third born.....	3
Fourth born.....	4
Other.....	5

Date of diagnosis: _____

Does this child have any other problems with his or her health?

Yes _____ What is it? _____

No _____

What is the mother's occupation? _____

What is the father's occupation? _____

How many years of education have each of the parents had?

Mother _____

Father _____

What is the religion in the family?

Protestant _____	Jewish _____
Catholic _____	Other _____

How frequently does the family attend religious services?

Weekly _____ Monthly _____ Rarely _____ Never _____

What is the yearly family income (before taxes)?

Less than \$19,999.....	1
\$20,000-\$39,999.....	2
\$40,000-\$59,999.....	3
\$60,000-\$79,999.....	4
\$80,000-\$99,999.....	5
More than or equal to \$100,000.....	6

CHIP

COPING HEALTH INVENTORY FOR PARENTS®

Hamilton I. McCubbin · Marilyn A. McCubbin · Robert S. Nevin · Elizabeth Cauble

PURPOSE

CHIP - The Coping Health Inventory for Parents was developed to record what parents find helpful or not helpful to them in the management of family life when one or more of its members is ill for a brief period or has a medical condition which calls for continued medical care. Coping is defined as personal or collective (with other individuals, programs) efforts to manage the hardships associated with health problems in the family.

DIRECTIONS

- To complete this inventory you are asked to read the list of "Coping behaviors" below, one at a time.
- For each coping behavior you used, please record how helpful it was.

How helpful was this coping behavior to you and/or your family: Circle one number

3 = *Extremely* helpful

2 = *Moderately* helpful

1 = *Minimally* helpful

0 = *Not* helpful

- For each coping behavior you did not use please record your "Reason."

Please record this by checking one of the reasons:

Chose not
to use it

or

Not
Possible

Please begin: Please read and record your decision for each and every Coping Behavior listed below

Coping Behaviors	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I do not cope this way because:	
					Chose Not to	Not Possible
1. Talking over personal feelings and concerns with spouse	3	2	1	0		
2. Engaging in relationships and friendships which help me to feel important and appreciated	3	2	1	0		
3. Trusting my spouse (or former spouse) to help support me and my child(ren)	3	2	1	0		
4. Sleeping	3	2	1	0		
5. Talking with the medical staff (nurses, social worker, etc.) when we visit the medical center	3	2	1	0		
6. Believing that my child(ren) will get better	3	2	1	0		
7. Working, outside employment	3	2	1	0		
8. Showing that I am strong	3	2	1	0		
9. Purchasing gifts for myself and/or other family members	3	2	1	0		
10. Talking with other individuals/parents in my same situation	3	2	1	0		
11. Taking good care of all the medical equipment at home	3	2	1	0		
12. Eating	3	2	1	0		
13. Getting other members of the family to help with chores and tasks at home	3	2	1	0		
14. Getting away by myself	3	2	1	0		
15. Talking with the doctor about my concerns about my child(ren) with the medical condition	3	2	1	0		
16. Believing that the medical center/hospital has my family's best interest in mind	3	2	1	0		
17. Building close relationships with people	3	2	1	0		
18. Believing in God	3	2	1	0		
19. Develop myself as a person	3	2	1	0		

Coping Behaviors	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I do not cope this way because	Chose Not to	Not Possible
20. Talking with other parents in the same type of situation and learning about their experiences	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
21. Doing things together as a family (involving all members of the family)	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
22. Investing time and energy in my job	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
23. Believing that my child is getting the best medical care possible	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
24. Entertaining friends in our home	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
25. Reading about how other persons in my situation handle things	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
26. Doing things with family relatives	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
27. Becoming more self reliant and independent	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
28. Telling myself that I have many things I should be thankful for	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
29. Concentrating on hobbies (art, music, jogging, etc.)	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
30. Explaining family situation to friends and neighbors so they will understand us	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
31. Encouraging child(ren) with medical condition to be more independent	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
32. Keeping myself in shape and well groomed	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
33. Involvement in social activities (parties, etc.) with friends	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
34. Going out with my spouse on a regular basis	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
35. Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
36. Building a closer relationship with my spouse	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
37. Allowing myself to get angry	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>
38. Investing myself in my child(ren)	3	2	1	0		<input type="checkbox"/>	<input type="checkbox"/>

Coping Behaviors	Extremely Helpful	Moderately Helpful	Minimally Helpful	Not Helpful	I do not cope this way because	
					Chose Not to	Not Possible
39. Talking to someone (not professional counselor/doctor) about how I feel	3	2	1	0		
40. Reading more about the medical problem which concerns me	3	2	1	0		
41. Trying to maintain family stability	3	2	1	0		
42. Being able to get away from the home care tasks and responsibilities for some relief	3	2	1	0		
43. Having my child with the medical condition seen at the clinic/hospital on a regular basis	3	2	1	0		
44. Believing that things will always work out	3	2	1	0		
45. Doing things with my children	3	2	1	0		

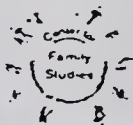
FACES II: Family Version

David H. Olson, Joyce Portner & Richard Bell

1 Almost Never	2 Once in Awhile	3 Sometimes	4 Frequently	5 Almost Always
-------------------	---------------------	----------------	-----------------	--------------------

Describe Your Family:

- ☐ 1. Family members are supportive of each other during difficult times.
- ☐ 2. In our family, it is easy for everyone to express his/her opinion.
- ☐ 3. It is easier to discuss problems with people outside the family than with other family members.
- ☐ 4. Each family member has input regarding major family decisions.
- ☐ 5. Our family gathers together in the same room.
- ☐ 6. Children have a say in their discipline.
- ☐ 7. Our family does things together.
- ☐ 8. Family members discuss problems and feel good about the solutions.
- ☐ 9. In our family, everyone goes his/her own way.
- ☐ 10. We shift household responsibilities from person to person.
- ☐ 11. Family members know each other's close friends.
- ☐ 12. It is hard to know what the rules are in our family.
- ☐ 13. Family members consult other family members on personal decisions.
- ☐ 14. Family members say what they want.
- ☐ 15. We have difficulty thinking of things to do as a family.
- ☐ 16. In solving problems, the children's suggestions are followed.
- ☐ 17. Family members feel very close to each other.
- ☐ 18. Discipline is fair in our family.
- ☐ 19. Family members feel closer to people outside the family than to other family members.
- ☐ 20. Our family tries new ways of dealing with problems.
- ☐ 21. Family members go along with what the family decides to do.
- ☐ 22. In our family, everyone shares responsibilities.
- ☐ 23. Family members like to spend their free time with each other.
- ☐ 24. It is difficult to get a rule changed in our family.
- ☐ 25. Family members avoid each other at home.
- ☐ 26. When problems arise, we compromise.
- ☐ 27. We approve of each other's friends.
- ☐ 28. Family members are afraid to say what is on their minds.
- ☐ 29. Family members pair up rather than do things as a total family.
- ☐ 30. Family members share interests and hobbies with each other.



Family Stress, Coping and Health Project
School of Human Ecology
1300 Linden Drive
University of Wisconsin-Madison
Madison, WI 53706

FIRM

FAMILY INVENTORY OF RESOURCES FOR MANAGEMENT

Hamilton L. McCubbin Joan K. Compas Jo A. Harkins

Purpose

FIRM - Family Inventory of Resources for Management was developed to record what social, psychological, community and financial resources families believe they have available to them in the management of family life.

Directions

To complete this inventory you are asked to read the list of "Family Statements" one at a time. In each statement, "family" means your immediate family (mother and/or father and children).

Then ask yourself: "How well does the statement describe our family situation?"

Then make your decision by circling one of the following

- 0 = Not At All This statement does not describe our family situation. This does not happen in our family.
- 1 = Minimally This statement describes our family situation only slightly. Our family may be like this once in a while.
- 2 = Moderately This statement describes our family situation fairly well. Our family is like this some of the time.
- 3 = Very Well This statement describes our family very accurately. Our family is like this most of the time.

Please begin - Please read and record your decision for each and every statement below.

Family statements:		Not at all	Minimally	Moderately	Very Well
1	We have money coming in from our investments (such as rental property, stocks, bonds, etc.)	0	1	2	3
2	Being physically tired much of the time is a problem in our family.	0	1	2	3
3	We have to nag each other to get things done.	0	1	2	3
4	We do not plan too far ahead because many things turn out to be a matter of good or bad luck anyway.	0	1	2	3
5	Our family is as well adjusted as any family in this world can be.	0	1	2	3
6	Having only one person in the family earning money is or would be a problem in our family.	0	1	2	3
7	It seems that members of our family take each other for granted.	0	1	2	3
8	Sometimes we feel we don't have enough control over the direction our lives are taking.	0	1	2	3

Family statements:	Not at all	Minimally	Moderately	Very Well	
9. Certain members of our family do all the giving, while others do all the taking	0	1	2	3	⊗
10. We depend almost entirely upon financial support from welfare or other public assistance programs	0	1	2	3	⊗
11. We seem to put off making decisions	0	1	2	3	⊗
12. Family members understand each other completely	0	1	2	3	
13. Our family is under a lot of emotional stress	0	1	2	3	⊗
14. Many things seem to interfere with family members being able to share concerns	0	1	2	3	⊗
15. Most of the money decisions are made by only one person in our family	0	1	2	3	⊗
16. There are times when family members do things that make other members unhappy	0	1	2	3	⊗
17. It seems that we have more illness (colds, flu, etc.) in our family than other people do	0	1	2	3	⊗
18. In our family some members have many responsibilities while others don't have enough	0	1	2	3	⊗
19. No one could be happier than our family when we are together	0	1	2	3	
20. It is upsetting to our family when things don't work out as planned	0	1	2	3	⊗
21. We depend almost entirely on income from alimony and/or child support	0	1	2	3	⊗
22. Being sad or "down" is a problem in our family	0	1	2	3	⊗
23. It is hard to get family members to cooperate with each other	0	1	2	3	⊗
24. If our family has any faults, we are not aware of them	0	1	2	3	
25. We depend almost entirely on social security retirement income	0	1	2	3	⊗
26. Many times we feel we have little influence over the things that happen to us	0	1	2	3	⊗
27. We have the same problems over and over—we don't seem to learn from past mistakes	0	1	2	3	⊗
28. One or more working members of our family are presently unemployed	0	1	2	3	⊗
29. There are things at home we need to do that we don't seem to get done	0	1	2	3	⊗
30. We feel our family is a perfect success	0	1	2	3	
31. We own land or property besides our place of residence	0	1	2	3	
32. We seem to be so involved with work and/or school activities that we don't spend enough time together as a family	0	1	2	3	⊗
33. We own (are buying) a home (single family, condominium, townhouse, etc.)	0	1	2	3	
34. There are times when we do not feel a great deal of love and affection for each other	0	1	2	3	⊗

Family statements:	Not at all	Minimally	Moderately	Very Well
35. If a close relative were having financial problems we feel we could afford to help them out	0	1	2	3
36. Friends seem to enjoy coming to our house for visits	0	1	2	3
37. We feel we have a good retirement income program	0	1	2	3
38. When we make plans we are almost certain we can make them work	0	1	2	3
39. In our family we understand what help we can expect from each other	0	1	2	3
40. We seem to have little or no trouble paying our bills on time	0	1	2	3
41. Our relatives seem to take from us, but give little in return	0	1	2	3
42. We would have no problem getting a loan at a bank if we wanted one	0	1	2	3
43. We feel we have enough money on hand to cover small unexpected expenses (under \$100)	0	1	2	3
44. When we face a problem, we look at the good and bad of each possible solution	0	1	2	3
45. The member(s) who earn our family income seem to have good employee benefits (such as paid insurance, stocks, car, education, etc.)	0	1	2	3
46. No matter what happens to us, we try to look at the bright side of things	0	1	2	3
47. We feel we are able to go out to eat occasionally without hurting our budget	0	1	2	3
48. We try to keep in touch with our relatives as much as possible	0	1	2	3
49. It seems that we need more life insurance than we have	0	1	2	3
50. In our family it is "okay" for members to show our positive feelings about each other	0	1	2	3
51. We feel we are able to make financial contributions to a good cause (needy people, church, etc.)	0	1	2	3
52. We seem to be happier with our lives than many families we know	0	1	2	3
53. It is "okay" for family members to express sadness by crying, even in front of others	0	1	2	3
54. When we need something that can't be postponed, we have money in savings to cover it	0	1	2	3
55. We discuss our decisions with other family members before carrying them out	0	1	2	3
56. Our relative(s) are willing to listen to your problems	0	1	2	3
57. We worry about how we would cover a large unexpected bill (for home, auto repairs, etc. for about \$100)	0	1	2	3
58. We get great satisfaction when we can help one another in our family	0	1	2	3
59. In our family we feel it is important to save for the future	0	1	2	3
60. The working members of our family seem to be respected by their co-workers	0	1	2	3

Family statements:	Not at all	Minimally	Moderately	Very Well
61. We have written checks knowing there wasn't enough money in the account to cover it	0	1	2	3
62. The members of our family respect each other	0	1	2	3
63. We save our extra spending money for special things	0	1	2	3
64. We feel confident that if our main breadwinner lost his/her job, (s)he could find another one	0	1	2	3
65. Members of our family are encouraged to have their own interests and abilities	0	1	2	3
66. Our relatives do and say things that make us feel appreciated	0	1	2	3
67. The members of our family are known to be good citizens and neighbors	0	1	2	3
68. We make an effort to help our relatives when we can	0	1	2	3
69. We feel we are financially better off now than we were 5 years ago	0	1	2	3

(1)	I can talk to my parents about my school work.	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
(2)	I feel other people my age are luckier than I am	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
(3)	I sometimes feel mad about my brother's/sister's diabetes	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
The reasons why it makes me mad are		_____				
_____		_____				
(4)	I worry that I can catch diabetes from my brother/sister	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
(5)	I feel my friends worry about catching diabetes from my brother/sister	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
(6)	I think about my brother's/sister's diabetes	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
Some things I think about are		_____				
_____		_____				
(7)	I wish I had known more about my brother's/sister's diabetes	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
(8)	I still wonder why my brother/sister got sick	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
(9)	I wish my parents would spend less time with my brother/sister	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
(10)	I wish I were sick too	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
(11)	I wish that there was something I could do to make my brother/sister feel better	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
(12)	I understand my parents have to spend more time with my sick brother/sister	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
(13)	I feel I have too much to do around the house since my brother/sister got sick	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
(14)	I am afraid of my brother's/sister's diabetes	NEVER	A LITTLE	SOMETIMES	A LOT	ALWAYS
Some things I am afraid of are		_____				
_____		_____				

ID Code # _____

- | | NEVER | A LITTLE | SOMETIMES | A LOT | ALWAYS |
|--|-------|----------|-----------|-------|--------|
| (15) Since my brother/sister got sick
I feel my parents ignore me | | | | | |
| (16) Since my brother/sister got sick
we don't do as many things as
a family | | | | | |
| (17) I wish my parents would spend
more time with me | | | | | |
| (18) I can talk to other people my age
about my brother's/sister's diabetes | | | | | |
| (19) I can talk to my parents about my
brother's/sister's diabetes | | | | | |
| (20) I can talk to other adults
(like my teachers) about
my brother's/sister's diabetes | | | | | |
| (21) I feel people are more interested
in my brother's/sister's diabetes
than me | | | | | |
| (22) I feel people don't care how I feel | | | | | |
| (23) I feel I don't want to bother my
parents about my worries | | | | | |
| (24) I wish I knew someone who
understands how I feel about
my brother's/sister's diabetes | | | | | |
| (25) My brother's/sister's diabetes
makes me sad | | | | | |

The reasons why it makes me sad are _____

- | | | | | | |
|---|-------|----------|-----------|-------|--------|
| (26) I can have a good time even though
my brother/sister is sick | NEVER | A LITTLE | SOMETIMES | A LOT | ALWAYS |
| (27) There are times when I forget that
my brother/sister has diabetes | NEVER | A LITTLE | SOMETIMES | A LOT | ALWAYS |
| (28) When I feel frustrated, mad, sad, etc
the things I do are | NEVER | A LITTLE | SOMETIMES | A LOT | ALWAYS |

- | | | | | | |
|--|-------|----------|-----------|-------|--------|
| (29) When my brother/sister got diabetes, my
parents told me about it | NEVER | A LITTLE | SOMETIMES | A LOT | ALWAYS |
|--|-------|----------|-----------|-------|--------|

The things I was told _____

DIRECTIONS: This is not a test! Do not put your name on this paper.

When some children feel stressed, nervous, or worried about something, they do some of the things listed below. Think about when **YOU** feel stressed, nervous or worried. Circle **HOW OFTEN** you do each of these things either before the stressful thing happens, while you feel stressed, or after the stressful thing is over. Then tell me **HOW MUCH** each thing helps you feel better when you feel stressed, nervous or worried.

Stressful Thing

	HOW OFTEN DO YOU DO THIS?				HOW MUCH DOES IT HELP?			
	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
1. Be by myself; be alone.								
2. Bite my nails or crack my knuckles.								
3. Cuddle my pet or stuffed animal.								
4. Cry or feel sad.								
5. Daydream.								
6. Do something about it.								
7. Do work around the house.								
8. Draw, write, or read something.								
9. Eat or drink.								
10. Fight with someone.								
11. Get mad.								

12. Hit, throw or break things.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
13. Pick on someone.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
14. Play a game or something.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
15. Play.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
16. Run or walk away.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
17. Say I'm sorry or tell the truth.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
18. Sleep, take a nap.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
19. Talk to myself.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
20. Talk to someone.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
21. Think about it.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
22. Try to forget about it.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
23. Try to relax, stay calm.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
24. Walk, run or ride my bike.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
25. Watch TV or listen to music.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot
26. Yell or scream.	Never	Once in a while	A lot	Most of the time	Never do it	Does not help	Helps a little	Helps a lot

What else would you add?

What I Am Like

Name _____ Age _____ Birthday _____ Month _____ Day _____ Group _____

Boy or Girl (circle which)

SAMPLE SENTENCE

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
(a)	<input type="checkbox"/>	<input type="checkbox"/>	Some kids would rather play outdoors in their spare time	BUT	Other kids would rather watch T.V.	<input type="checkbox"/> <input type="checkbox"/>
1.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids feel that they are very <i>good</i> at their school work	BUT	Other kids <i>worry</i> about whether they can do the school work assigned to them.	<input type="checkbox"/> <input type="checkbox"/>
2.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids find it <i>hard</i> to make friends	BUT	Other kids find it's pretty easy to make friends.	<input type="checkbox"/> <input type="checkbox"/>
3.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids do very <i>well</i> at all kinds of sports	BUT	Other kids <i>don't</i> feel that they are very good when it comes to sports.	<input type="checkbox"/> <input type="checkbox"/>
4.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are <i>happy</i> with the way they look	BUT	Other kids are <i>not</i> happy with the way they look.	<input type="checkbox"/> <input type="checkbox"/>
5.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids often do <i>not</i> like the way they <i>behave</i>	BUT	Other kids usually <i>like</i> the way they behave.	<input type="checkbox"/> <input type="checkbox"/>
6.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are often <i>unhappy</i> with themselves	BUT	Other kids are pretty <i>pleased</i> with themselves	<input type="checkbox"/> <input type="checkbox"/>
7.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids feel like they are <i>just as smart</i> as other kids their age	BUT	Other kids aren't so sure and <i>wonder</i> if they are as smart.	<input type="checkbox"/> <input type="checkbox"/>
8.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids have <i>alot</i> of friends	BUT	Other kids <i>don't</i> have very many friends.	<input type="checkbox"/> <input type="checkbox"/>

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
9.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids wish they could be alot better at sports	BUT	Other kids feel they are good enough at sports.	<input type="checkbox"/>	<input type="checkbox"/>
10.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are <i>happy</i> with their height and weight	BUT	Other kids wish their height or weight were <i>different</i> .	<input type="checkbox"/>	<input type="checkbox"/>
11.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids usually do the <i>right</i> thing	BUT	Other kids often <i>don't</i> do the right thing.	<input type="checkbox"/>	<input type="checkbox"/>
12.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids <i>don't</i> like the way they are leading their life	BUT	Other kids <i>do</i> like the way they are leading their life.	<input type="checkbox"/>	<input type="checkbox"/>
13.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are pretty <i>slow</i> in finishing their school work	BUT	Other kids can do their school work <i>quickly</i> .	<input type="checkbox"/>	<input type="checkbox"/>
14.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids would like to have alot more friends	BUT	Other kids have as many friends as they want.	<input type="checkbox"/>	<input type="checkbox"/>
15.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids think they could do well at just about any new sports activity they haven't tried before	BUT	Other kids are afraid they might <i>not</i> do well at sports they haven't ever tried.	<input type="checkbox"/>	<input type="checkbox"/>
16.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids wish their body was <i>different</i>	BUT	Other kids <i>like</i> their body the way it is.	<input type="checkbox"/>	<input type="checkbox"/>
17.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids usually <i>act</i> the way they know they are <i>supposed</i> to	BUT	Other kids often <i>don't</i> act the way they are supposed to.	<input type="checkbox"/>	<input type="checkbox"/>
18.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are <i>happy</i> with themselves as a person	BUT	Other kids are often <i>not</i> happy with themselves.	<input type="checkbox"/>	<input type="checkbox"/>
19.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids often <i>forget</i> what they learn	BUT	Other kids can remember things <i>easily</i> .	<input type="checkbox"/>	<input type="checkbox"/>
20.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids are always doing things with <i>alot</i> of kids	BUT	Other kids usually do things <i>by themselves</i> .	<input type="checkbox"/>	<input type="checkbox"/>

Really
True
for me

Sort of
True
for me

Sort of
True
for me

Really
True
for me

- | | | | | | | | |
|-----|--------------------------|--------------------------|---|-----|--|--------------------------|--------------------------|
| 21. | <input type="checkbox"/> | <input type="checkbox"/> | Some kids feel that they are <i>better</i> than others their age at sports | BUT | Other kids <i>don't</i> feel they can play as well. | <input type="checkbox"/> | <input type="checkbox"/> |
| 22. | <input type="checkbox"/> | <input type="checkbox"/> | Some kids wish their physical appearance (how they look) was <i>different</i> | BUT | Other kids <i>like</i> their physical appearance the way it is. | <input type="checkbox"/> | <input type="checkbox"/> |
| 23. | <input type="checkbox"/> | <input type="checkbox"/> | Some kids usually get in <i>trouble</i> because of things they do | BUT | Other kids usually <i>don't</i> do things that get them in trouble. | <input type="checkbox"/> | <input type="checkbox"/> |
| 24. | <input type="checkbox"/> | <input type="checkbox"/> | Some kids <i>like</i> the kind of <i>person</i> they are | BUT | Other kids often wish they were someone else. | <input type="checkbox"/> | <input type="checkbox"/> |
| 25. | <input type="checkbox"/> | <input type="checkbox"/> | Some kids do <i>very well</i> at their classwork | BUT | Other kids <i>don't</i> do very well at their classwork. | <input type="checkbox"/> | <input type="checkbox"/> |
| 26. | <input type="checkbox"/> | <input type="checkbox"/> | Some kids wish that more people their age liked them | BUT | Other kids feel that most people their age <i>do</i> like them. | <input type="checkbox"/> | <input type="checkbox"/> |
| 27. | <input type="checkbox"/> | <input type="checkbox"/> | In games and sports some kids usually <i>watch</i> instead of play | BUT | Other kids usually <i>play</i> rather than just watch. | <input type="checkbox"/> | <input type="checkbox"/> |
| 28. | <input type="checkbox"/> | <input type="checkbox"/> | Some kids wish something about their face or hair looked <i>different</i> | BUT | Other kids <i>like</i> their face and hair the way they are. | <input type="checkbox"/> | <input type="checkbox"/> |
| 29. | <input type="checkbox"/> | <input type="checkbox"/> | Some kids do things they know they <i>shouldn't</i> do | BUT | Other kids <i>hardly ever</i> do things they know they shouldn't do. | <input type="checkbox"/> | <input type="checkbox"/> |
| 30. | <input type="checkbox"/> | <input type="checkbox"/> | Some kids are very <i>happy</i> being the way they are | BUT | Other kids wish they were <i>different</i> . | <input type="checkbox"/> | <input type="checkbox"/> |
| 31. | <input type="checkbox"/> | <input type="checkbox"/> | Some kids have <i>trouble</i> figuring out the answers in school | BUT | Other kids almost <i>always</i> can figure out the answers. | <input type="checkbox"/> | <input type="checkbox"/> |
| 32. | <input type="checkbox"/> | <input type="checkbox"/> | Some kids are <i>popular</i> with others their age | BUT | Other kids are <i>not</i> very popular. | <input type="checkbox"/> | <input type="checkbox"/> |

	Really True for me	Sort of True for me			Sort of True for me	Really True for me
33.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids <i>don't</i> do well at new outdoor games	BUT	Other kids are <i>good</i> at new games right away.	<input type="checkbox"/>
34.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids think that they are good looking	BUT	Other kids think that they are not very good looking.	<input type="checkbox"/>
35.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids behave themselves very well	BUT	Other kids often find it hard to behave themselves.	<input type="checkbox"/>
36.	<input type="checkbox"/>	<input type="checkbox"/>	Some kids <i>are</i> not very happy with the way they do alot of things	BUT	Other kids think the way they do things is <i>fine</i> .	<input type="checkbox"/>

CD INVENTORY

NAME: _____

DATE: _____

CASE NO.:

--	--

--	--	--

INTERVIEW NO.:

--	--

FORM NO.:

0	8
---	---

KIDS SOMETIMES HAVE DIFFERENT FEELINGS AND IDEAS.

THIS FORM LISTS THE FEELINGS AND IDEAS IN GROUPS. FROM EACH GROUP, PICK ONE SENTENCE THAT DESCRIBES YOU BEST FOR THE PAST TWO WEEKS.

AFTER YOU PICK A SENTENCE FROM THE FIRST GROUP, GO ON TO THE NEXT GROUP.

THERE IS NO RIGHT ANSWER OR WRONG ANSWER. JUST PICK THE SENTENCE THAT BEST DESCRIBES THE WAY YOU HAVE BEEN RECENTLY. PUT A MARK LIKE THIS **X** NEXT TO YOUR ANSWER. PUT THE MARK IN THE BOX NEXT TO THE SENTENCE THAT YOU PICK.

HERE IS AN EXAMPLE OF HOW THIS FORM WORKS. TRY IT. PUT A MARK NEXT TO THE SENTENCE THAT DESCRIBES YOU BEST.

EXAMPLE:

- | | |
|--------------------------|------------------------------|
| <input type="checkbox"/> | I READ BOOKS ALL THE TIME |
| <input type="checkbox"/> | I READ BOOKS ONCE IN A WHILE |
| <input type="checkbox"/> | I NEVER READ BOOKS |

REMEMBER, PICK OUT THE SENTENCES THAT DESCRIBE YOUR FEELINGS AND IDEAS IN THE PAST TWO WEEKS.

1. ☐ I AM SAD ONCE IN A WHILE
☐ I AM SAD MANY TIMES
☐ I AM SAD ALL THE TIME
2. ☐ NOTHING WILL EVER WORK OUT FOR ME
☐ I AM NOT SURE IF THINGS WILL WORK OUT FOR ME
☐ THINGS WILL WORK OUT FOR ME O.K.
3. ☐ I DO MOST THINGS O.K.
☐ I DO MANY THINGS WRONG
☐ I DO EVERYTHING WRONG
4. ☐ I HAVE FUN IN MANY THINGS
☐ I HAVE FUN IN SOME THINGS
☐ NOTHING IS FUN AT ALL
5. ☐ I AM BAD ALL THE TIME
☐ I AM BAD MANY TIMES
☐ I AM BAD ONCE IN A WHILE
6. ☐ I THINK ABOUT BAD THINGS HAPPENING TO ME ONCE IN A WHILE
☐ I WORRY THAT BAD THINGS WILL HAPPEN TO ME
☐ I AM SURE THAT TERRIBLE THINGS WILL HAPPEN TO ME
7. ☐ I HATE MYSELF
☐ I DO NOT LIKE MYSELF
☐ I LIKE MYSELF

8. ☐ ALL BAD THINGS ARE MY FAULT
☐ MANY BAD THINGS ARE MY FAULT
☐ BAD THINGS ARE NOT USUALLY MY FAULT
9. ☐ I DO NOT THINK ABOUT KILLING MYSELF
☐ I THINK ABOUT KILLING MYSELF BUT I WOULD NOT DO IT
☐ I WANT TO KILL MYSELF
10. ☐ I FEEL LIKE CRYING EVERYDAY
☐ I FEEL LIKE CRYING MANY DAYS
☐ I FEEL LIKE CRYING ONCE IN A WHILE
11. ☐ THINGS BOTHER ME ALL THE TIME
☐ THINGS BOTHER ME MANY TIMES
☐ THINGS BOTHER ME ONCE IN A WHILE
12. ☐ I LIKE BEING WITH PEOPLE
☐ I DO NOT LIKE BEING WITH PEOPLE MANY TIMES
☐ I DO NOT WANT TO BE WITH PEOPLE AT ALL
13. ☐ I CANNOT MAKE UP MY MIND ABOUT THINGS
☐ IT IS HARD TO MAKE UP MY MIND ABOUT THINGS
☐ I MAKE UP MY MIND ABOUT THINGS EASILY
14. ☐ I LOOK O.K.
☐ THERE ARE SOME BAD THINGS ABOUT MY LOOKS
☐ I LOOK UGLY
15. ☐ I HAVE TO PUSH MYSELF ALL THE TIME TO DO MY SCHOOLWORK
☐ I HAVE TO PUSH MYSELF MANY TIMES TO DO MY SCHOOLWORK
☐ DOING SCHOOLWORK IS NOT A BIG PROBLEM

REMEMBER, DESCRIBE HOW YOU HAVE BEEN IN THE PAST TWO WEEKS.

16. ☐ I HAVE TROUBLE SLEEPING EVERY NIGHT
☐ I HAVE TROUBLE SLEEPING MANY NIGHTS
☐ I SLEEP PRETTY WELL
17. ☐ I AM TIRED ONCE IN A WHILE
☐ I AM TIRED MANY DAYS
☐ I AM TIRED ALL THE TIME
18. ☐ MOST DAYS I DO NOT FEEL LIKE EATING
☐ MANY DAYS I DO NOT FEEL LIKE EATING
☐ I EAT PRETTY WELL
19. ☐ I DO NOT WORRY ABOUT ACHES AND PAINS
☐ I WORRY ABOUT ACHES AND PAINS MANY TIMES
☐ I WORRY ABOUT ACHES AND PAINS ALL THE TIME
20. ☐ I DO NOT FEEL ALONE
☐ I FEEL ALONE MANY TIMES
☐ I FEEL ALONE ALL THE TIME
21. ☐ I NEVER HAVE FUN AT SCHOOL
☐ I HAVE FUN AT SCHOOL ONLY ONCE IN A WHILE
☐ I HAVE FUN AT SCHOOL MANY TIMES
22. ☐ I HAVE PLENTY OF FRIENDS
☐ I HAVE SOME FRIENDS BUT I WISH I HAD MORE
☐ I DO NOT HAVE ANY FRIENDS

23. ☐ MY SCHOOL WORK IS ALRIGHT
☐ MY SCHOOLWORK IS NOT AS GOOD AS BEFORE
☐ I DO VERY BADLY IN SUBJECTS I USED TO BE GOOD IN
24. ☐ I CAN NEVER BE AS GOOD AS OTHER KIDS
☐ I CAN BE AS GOOD AS OTHER KIDS IF I WANT TO
☐ I AM JUST AS GOOD AS OTHER KIDS
25. ☐ NOBODY REALLY LOVES ME
☐ I AM NOT SURE IF ANYBODY LOVES ME
☐ I AM SURE THAT SOMEBODY LOVES ME
26. ☐ I USUALLY DO WHAT I AM TOLD
☐ I DO NOT DO WHAT I AM TOLD MOST TIMES
☐ I NEVER DO WHAT I AM TOLD
27. ☐ I GET ALONG WITH PEOPLE
☐ I GET INTO FIGHTS MANY TIMES
☐ I GET INTO FIGHTS ALL THE TIME

THE END

THANK YOU FOR FILLING OUT THIS FORM

SUM: _____

ADMINISTRATION: O. INDIVIDUAL
I. GROUP

Covariance Matrix

	CDI	SCSIFRQ	SCSIEFF	SPQKNOW	SPQPER	SPQMOD
	-----	-----	-----	-----	-----	-----
CDI	27.14					
SCSIFRQ	0.31	67.90				
SCSIEFF	-4.80	59.11	88.17			
SPQKNOW	1.32	6.42	6.60	11.09		
SPQPER	7.83	7.32	3.73	3.81	18.23	
SPQMOD	4.45	8.79	8.11	9.90	10.62	23.52
COHESION	-4.63	0.43	7.80	1.93	-0.29	4.27
ADAPT	-3.38	2.33	5.24	0.69	-1.89	5.00
COHES	-3.74	0.75	7.32	-0.42	0.94	1.90
SOCIAL	-4.34	9.72	11.15	1.55	3.17	5.13
COMUN	-1.32	3.04	2.39	1.65	1.45	4.44
RESOURC	-1.78	-0.72	3.43	-0.29	0.22	1.36

Covariance Matrix

	COHESION	ADAPT	COHES	SOCIAL	COMUN	RESOURC
	-----	-----	-----	-----	-----	-----
COHESION	69.06					
ADAPT	41.55	46.65				
COHES	10.44	8.62	38.32			
SOCIAL	4.16	12.14	25.81	65.29		
COMUN	0.51	3.58	9.66	8.17	10.11	
RESOURC	9.78	5.79	4.17	1.12	1.11	7.02



**HARVEY CUSHING/JOHN HAY WHITNEY
MEDICAL LIBRARY**

MANUSCRIPT THESES

Unpublished theses submitted for the Master's and Doctor's degrees and deposited in the Medical Library are to be used only with due regard to the rights of the authors. Bibliographical references may be noted, but passages must not be copied without permission of the authors, and without proper credit being given in subsequent written or published work.

This thesis by
has been used by the following person, whose signatures attest their acceptance of the above restrictions.

NAME AND ADDRESS

DATE

